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LOYOLA UNIVERSITY CHICAGO

RETRIEVING AND REIMAGINING SANCTUARY AND SOLIDARITY:  
RACIAL DISPARITIES IN INFANT MORTALITY

A DISSERTATION SUBMITTED TO  
THE FACULTY OF THE GRADUATE SCHOOL  
IN CANDIDACY FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY

PROGRAM IN THEOLOGY

BY

ALYSON ISAKSSON CAPP

CHICAGO, IL

MAY 2019

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To Pete and Eva

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## CHAPTER ONE

### “WHY ARE OUR BABIES DYING?”: INFANT MORTALITY IN MILWAUKEE

I first became aware of the injustices that contribute to infant mortality in 2012. I was living in Milwaukee, going to school for my master’s degree, and also working for an oral health program in elementary and middle schools. I remember turning on the news one night and hearing a story about an infant who died due to suffocation while sleeping in an adult bed with his parent. Images of smiling Milwaukee kids I had met through my work as a dental assistant flooded my mind as I considered whether the infant could be a sibling, cousin, or neighbor of one of my patients. The news story gave me the impression that co-sleeping was a major cause of infant death in Milwaukee, especially for African Americans babies.<sup>1</sup> I was outraged. My gut

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<sup>1</sup>I use both terms Black and African American to refer to US-residing descendants of Africans, many of whom were brought to the US from Africa during the slave trade. I have landed on this approach after listening to how people in Milwaukee describe themselves and their use of both of these descriptors, often interchangeably. I recognize that people of African descent from other African diaspora countries may not be comfortable with using either term to refer to their ethnicity. In all cases when writing about a real person I attempt to reflect how that person self-identifies. I capitalize this term to recognize the existence of a cultural group that shares some common experiences related to being Black in America. I am aware that some scholars I draw from do not capitalize Black or White (e.g. Bryan Massingale, Karen Lebacqz) and that some capitalize Black but do not capitalize White (e.g. Aana Marie Vigen, Jennifer Harvey). I recognize that many White scholars capitalize Black to show respect for Black culture, and do not capitalize White as an intentional grammatical distinction that pushes back against social norms where the balance of respect is often tipped in favor of White people. While I agree that this choice makes sense, I am choosing to capitalize White to emphasize that White culture does exist and its acceptance as the underlying norm needs to be questioned. I use the term White when referring to the cultural group of light-skinned, descendants of mostly European ancestors who share some common experiences in the US based on skin color, usually experiences of privilege. This choice reflects the style of Jeannine Hill Fletcher, systematic theologian and author of *The Sin of White Supremacy: Christianity, Racism, and Religious Diversity in America* (Maryknoll: Orbis, 2017). My purpose in capitalizing both Black and White is to attempt to recognize both Black and White culture as co-existing cultural phenomena, and especially to prompt White people to think about what it means to be part of White culture. I am aware that there are ongoing discussions among Black authors and scholars about using these terms, as well as between Black and White scholars. The knowledge that Neo-Nazis capitalize the term White as a way to breed hate gives me pause. However, I believe that context matters, and White supremacists utilize juxtaposition by not capitalizing Black, which I do not do. Capitalizing both Black and White in this dissertation is

reaction was to lay the blame at the feet of the parents. “How could a parent be so irresponsible, so neglectful?” I fumed. It then occurred to me that perhaps I should explore the issue further before assuming that the root cause of Milwaukee’s dismal infant mortality rate was “bad parenting.”

So, I did a little research. I was disheartened to learn that Milwaukee has an infant mortality rate that is worse than many places around the globe, including both developed and developing countries.<sup>2</sup> I was also surprised to learn that co-sleeping was not the main cause—not even close. I learned that infant deaths related to sudden infant death syndrome (SIDS), overlay, or accidental suffocation only accounted for 18% of all infant deaths in Milwaukee from 2005-2008.<sup>3</sup> I began to ask myself questions: What about the other 82%? Who was responsible for those deaths?

I then learned that complications of prematurity accounted for 54% of infant deaths during that time period.<sup>4</sup> This means that most babies who die in a given year do so before ever coming home from the hospital. These babies, who die in labor and delivery units or neonatal intensive care units (NICUs), do not make headlines on the nightly news. I further learned that prematurity is affected by multiple intertwined risk factors that are not solely within the control

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meant to prompt discussions about equity and racial justice, encouraging our minds to consider both Black and White culture as relevant and intermixing realities we must pay attention to when confronting infant mortality.

<sup>2</sup>K. Michalski, J. Gathirimu, A. Benton, G. Swain, E. Gass, E. Ngui. 2010 Milwaukee Fetal Infant Mortality Review Report. City of Milwaukee Health Department, December 2010, 9, [https://www.milwaukee.gov/2010\\_FIMR\\_Report.pdf](https://www.milwaukee.gov/2010_FIMR_Report.pdf) (accessed September 11, 2018).

<sup>3</sup>Ibid., 13.

<sup>4</sup>Ibid.

of parents. As I dug deeper, it became clear to me that socioeconomic and racial/ethnic disparities loom large in the underlying causes of infant deaths in Milwaukee.

Reflecting now on my presumption years ago that parents were to blame for the majority of infant deaths in Milwaukee, I realize how my own bias as a White, middle-class, college-educated young woman played a part in the snap judgement that I made. I grew up in the countryside and small cities of west-central Wisconsin, where most people are White like me. Though poverty existed in my hometown, it did not encroach much upon my worldview.<sup>5</sup> I had never really considered the effects of racial segregation and poverty on health until I moved to Milwaukee. On the job, I was struck by the vast differences between my childhood and that of my patients. Most of them received free or reduced price lunches based on their family's low income; many of my patients were Black children; and all of them lived in the city denounced as the worst place for African American children to grow up.<sup>6</sup>

Yet, despite the differences between our upbringings, there were many similarities between the children I met and my childhood self. Through listening to their stories about what they've learned and what they want to be and do, I was reminded of the way I looked at the world in second grade: with wonder, excitement, and a sense that incredible possibilities awaited me. It became evident to me that these possibilities are not equal for all, especially if the playing field is precipitous from the start.

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<sup>5</sup>According to recent estimates, Eau Claire, WI—where I went to high school—is 93.1% White, and 18.7% of the population lives below the poverty line. Compare this to Milwaukee, which is 44.8% White, 40% Black or African American, and where 28.7% of the population lives below the poverty line. United States Census Bureau, American Fact Finder, <https://factfinder.census.gov/faces/nav/jsf/pages/index.xhtml> (accessed August 15, 2017).

<sup>6</sup>Wisconsin Council on Children & Families, "Race for Results: Wisconsin's Need to Reduce Racial Disparities," Fall 2014, <http://www.wccf.org/assets/RaceForResults.pdf> (accessed September 16, 2016).

Now as the mother of an infant myself, I identify with other Milwaukee parents. I understand the difficulty of wanting the best for my child and not knowing whose advice to take, which sources to trust, and negotiating when and how to ask for help. I also know how it feels to behold the great mystery and miracle that is pregnancy and childbirth, which evokes incredible humility. While we can try to do “all the right things,” it is unsettling to learn that we parents are not in complete control of our children’s well-being. Looking back on my condemnation of Milwaukee parents, I see that I was being naïve. The outrage I felt then was not false, but misdirected. In what follows, I redirect my outrage toward dismantling the social structures that allow infant mortality and the disparities therein to persist.

I first met Mary Evans,<sup>7</sup> parish nurse at a local Catholic health system, when I began a fellowship in health care ethics in 2014. She identifies as a Christian African American woman who has lived in Milwaukee all of her life. I told her about my research interests in infant mortality, and she let me know about the work she has been doing with pregnant women, new mothers, and their families in churches over the past twenty years. Mary helped me to understand the complexities that underlie Milwaukee’s infant mortality program, and has encouraged me in this work since then.

In the summer of 2017, we met at the church that houses the food pantry and hypertension clinic Mary runs as part of her role through the parish nursing program. As a Church of God in Christ (COGIC) church, it is part of the largest Pentecostal denomination in the United States made up of primarily African American congregants. Mary unlocked the

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<sup>7</sup>Evans, Mary [pseud.]. Interviewed by author, June 5, 2017, Milwaukee, WI.

church door and invited me inside. We took a right past the sanctuary—thick red carpeting, old oak woodwork, the distinct smell of an established church—and sat at a conference table arm’s distance from the last row of pews. Mary has been working with the Strong Baby Sanctuary program, a community collaboration aimed at helping more babies celebrate their first birthdays, since its inception in 2015. During our conversation, we talked about the stressors faced by women and families living in Milwaukee’s inner city: poverty, food deserts, incarceration, violence, racial segregation, social isolation. Mary said, “I think we need to seek God and ask him, “Why are our babies dying?” We have to find out... I don’t know if it’s the environment that we live in now, but something’s not right.” Mary went on to describe her neighborhood growing up in Milwaukee, where teachers and principals lived on the same streets as the students they taught. In her mind, segregation, both racial/ethnic and socioeconomic, was not as widespread then as it is now. At a luncheon later that month that introduced churches to the Strong Baby Sanctuary program, Mary was interviewed by a local newscaster. When asked about Milwaukee’s infant mortality rate, Mary stated, “It keeps me up at night.”

### **Central Arguments and Structure**

Mary’s visceral feeling that something’s not right—indeed, things are so *wrong* that she cannot sleep—fuels my research. This project aims to help answer her question, “Why are our babies dying?” I am studying infant mortality because I want to discover the roles health departments, health care systems, and churches can play in eliminating the racial disparity between Black and White infants.<sup>8</sup> I am especially interested in how faith-based communities

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<sup>8</sup>While *de jure* segregation had its end as a result of the 1960s Civil Rights Movement, *de facto* segregation of Black and African American families endures and can be traced through to existing racial health disparities.

can participate in constructive ways to break down racial/ethnic and socioeconomic barriers that contribute to this disparity. I envision that this work will occur on many levels: I expect to find that campaigning for policy changes that affect socioeconomic factors, hosting teach-ins on racism and White privilege, and fostering support groups that bring together pregnant women and new families from different socioeconomic and racial/ethnic backgrounds may all be concurrent practices my project recommends. These activities bring what it means to be church outside the traditional norms of Sunday worship service and weekly Bible study—indeed, as an answer to the call that church *should* entail more than these important but stock activities. My hope is that this work will help shape how faith-based community partners engage constructively in practices to reduce infant mortality, and encourage secular community partners to see faith-based partners as having a valid contribution to make.

Indeed, racial disparity in infant mortality rates is a significant moral issue, particularly for Christians. Being committed to recognizing the *imago Dei* in each and every human being, especially the most vulnerable, means naming all preventable infant deaths as unspeakably tragic. The fact that these deaths occur more often within Black families, calls Christians to denounce this situation as unjust, and to name its contributing factors as evils. We can do so by following in the footsteps of Christian ethicists who are attentive to how race and privilege shape social relationships. For example, White Christian feminist ethicist Karen Lebacqz makes a compelling case for recognizing the injustices separating people based on race in everyday life.

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Socioeconomic disparities resulting from unjust social structures based on race will be further discussed later in this chapter.

She advocates for making these injustices the starting place for creating a more just world.<sup>9</sup>

Womanist theologian and ethicist Emilie Townes names evil as a cultural production that perpetuates structural inequalities and forms of oppression.<sup>10</sup> Following Lebacqz and Townes, if we start by naming Milwaukee's racial disparity in infant mortality as unjust, then call out those structures that allow it to persist as evil, Christian communities—especially White Christian communities—will no longer be able to ignore the role that privilege plays in stacking the deck against Black families.

Moreover, the persistence of this disparity shows that old ways of looking at this problem are insufficient. Most strategies employed during the last ten years aimed at reducing infant mortality have focused on educating pregnant women and parents and helping them meet the immediate needs of infants. While overall infant mortality rates during this timeframe have decreased, they have not met target levels. Of greater concern, the gap in infant mortality between Black infants and their White and Hispanic counterparts has widened.<sup>11</sup> Given the failure to close this gap, new practices and partnerships must be unearthed and put into motion.

What I hope to show in this project is that strategies aimed at building interracial solidarity within a community will be fruitful for reducing the racial disparity in infant mortality. A commitment to interracial solidarity would necessitate the interrogation of social structures and

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<sup>9</sup>Karen Lebacqz, *Justice in an Unjust World: Foundations for a Christian Approach to Justice* (Minneapolis: Fortress Press, 1987), 11.

<sup>10</sup>Emilie M. Townes, *Womanist Ethics and the Cultural Production of Evil* (New York: Palgrave Macmillan, 2006), 4.

<sup>11</sup>Ngui, E, et al, 2017 City of Milwaukee Fetal Infant Mortality Review Report, Milwaukee Health Department and Joseph J. Zilber School of Public Health, April 2017, 6, <http://city.milwaukee.gov/ImageLibrary/Groups/healthAuthors/ADMIN/PDFs/PressReleases/2017/FIMRReport2017FINAL.pdf> (accessed 08/23/2017).

power dynamics that perpetuate differences in health status and mortality based on race. Rather than blaming parents and assuming they need to take a lesson on good behavior, those of us in places of relative social and racial privilege might start by looking in the mirror. Those of us privileged enough to be in places that can influence how resources are allocated to tackle this problem need to re-evaluate how our initiatives are falling short. Unconscious biases related to race, class, and gender, when unchecked, may be creating unanticipated stumbling blocks, and our unawareness of cultural differences may be advancing a silent agenda of divisiveness and apathy.

Therefore, this dissertation represents a theo-ethical exploration of policy, health, and religious practices aimed at fostering ecumenical, interreligious, and secular partnership and common ground in order to confront and ameliorate racial disparities in infant mortality.<sup>12</sup> One argument that informs this work is that by learning from women from resource-stressed contexts, as well as volunteers and professionals who work with them, about how they understand the causes and risk factors for infant mortality, churches will be able to lift up practices from their respective theological traditions that are fruitful for enacting solidarity as they create sanctuaries for strong babies. The intersection of race, class, and gender makes it difficult to pinpoint exactly which strategies will be helpful for correcting this injustice. Redistribution of resources is one part; however, we will see that this disparity exists between White and Black women with

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<sup>12</sup>The construct “theo-ethical” represents a particular vantage point for ethical analysis that acknowledges the foundational role Christian values and practices can play in ethical decision-making, character development, and community building. While this dissertation does not speak specifically to interreligious approaches to infant mortality, the practices discussed (though grounded in Christian traditions) have the potential to resonate with important concepts of justice and respect present within non-Christian religious traditions as well as secular approaches to women and infant’s health.



similar socioeconomic statuses. Therefore race itself looms large in infant mortality, and setting a course toward a justice must include concern for interracial solidarity.

Thus, the purpose of this dissertation is two-pronged: 1) to investigate the relationship between Christian practices and specific public health practices that are successful in reducing infant mortality; and 2) to draw out and make explicit theo-ethical images in a tangible way that unites, inspires, and motivates communities around these successful practices as they work to reduce infant mortality and end racial disparities in infant mortality. These purposes will be accomplished through discussing barriers and opportunities to healthy pregnancies and babies with the collaborators in this study, selecting those best practices that resonate with theological commitments, and presenting these practices in a way that motivates Christians and secular partners to work together. I expect to find practices that will be aimed at helping pregnant women and families on the policy, community, and individual levels.

Three main questions focus this research: 1) How do socioeconomic and racial/ethnic factors relate to infant mortality in the concrete lives of Black women, and what insights do they, along with those who work to reduce infant mortality, have for combating this disparity? 2) How can particular theological norms coupled with public health practices inform the work of Strong Baby Sanctuaries and their community partners toward their goals of reducing infant mortality and ending racial disparities in infant mortality? 3) How can these practices be presented so that ecumenical and secular partners, as well as the greater community, are motivated to support this cause? My purpose is to inform moral imagination in a way that inspires a commitment to practices that can end racial disparities in infant mortality, and offer practical steps toward this goal. I argue that through strategic practices informed by sound data and reflective of concrete

experiences, health care systems, government agencies, and churches can partner with women to work together to end racial disparities in infant mortality.

In all, this dissertation will explore the contributions that faith communities can make in repairing social relationships that can help infants and their families not only survive, but flourish. To start with an accurate sense of what is going on, the rest of this chapter presents a snapshot of the problem of infant mortality in the particular location of Milwaukee, Wisconsin. After discussing the dismal statistics around infant mortality, I will introduce readers to relevant socioeconomic disparities in Milwaukee, followed by specific racial disparities and the interrelated manifestation of White privilege. Finally, the Strong Baby Sanctuary program will then be described in detail. Particular attention will be paid to the challenges and opportunities this program has to make a difference in the lives of Milwaukee's infants, women, and families.

Chapter Two will introduce frameworks and principles for Christian bioethics that can help shape an ethical response to infant mortality. Ethnography will also be discussed as the methodology guiding this research project, and the specific research design will be delineated. Chapter Three invites the reader to listen to and learn from Milwaukee mothers who are members of a Strong Baby Sanctuary support group. Their thoughts and experiences will be followed in Chapter Four by the voices of Strong Baby Sanctuary leaders, public health personnel, and physicians, all of whom are committed to reducing infant mortality and the racial/ethnic disparities therein. Finally, Chapter Five envisions the key components of a contextualized solidarity, along with practical recommendations, that can respond to Milwaukee's infant mortality crisis. It is my hope that these practices will represent new and creative ways to dismantle the structures that enable dismal infant mortality rates to persist.

### **“Something’s Not Right”: Infant Mortality in the US and Milwaukee**

Infant mortality rates (IMRs) are generally offered as barometric readings of the well-being of populations.<sup>13</sup> In the United States, the IMR is 5.8 infant deaths per 1,000 live births. This rate is higher than in Canada, Greece, Belarus, Israel, and South Korea, among many others.<sup>14</sup> In Milwaukee, the IMR is 9.8—four points higher than the national average. Milwaukee’s IMR is higher than those found in countries including Sri Lanka, Bulgaria, Kuwait, and Chile, and of other US cities like Baltimore, Philadelphia, Chicago, Houston, and New York City.<sup>15</sup> When comparing IMRs in the US based on race and ethnicity, Black infants die more often than any other racial/ethnic group, and *twice* as often as White and Hispanic infants.<sup>16</sup> Black infants in Milwaukee die *three times* as often as White and Hispanic infants, indeed more often than any other racial/ethnic group in the city.<sup>17</sup>

Levels of well-being within a single population are not the same for all. In the US, where we have more wealth and medical technologies than countries with lower IMRs, it is not only unfortunate, sad, or troubling that so many of our most vulnerable citizens do not live to see their first birthdays. We can go further to decry these infant deaths as an injustice. The racial disparity in infant mortality further compounds this injustice for Black infants and their families. Black

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<sup>13</sup>Center for Disease Control and Prevention, “Infant Mortality,” <https://www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.html> (accessed 07/21/2017).

<sup>14</sup>Central Intelligence Agency, “Country Comparison: Infant Mortality Rate,” <https://www.cia.gov/library/publications/the-world-factbook/rankorder/2091rank.html> (accessed 07/21/2017).

<sup>15</sup>Ngui et al., 7.

<sup>16</sup>Matthews, T.J. et al, “Infant Mortality Statistics From the 2013 Period Linked Birth/Infant Death Data Set,” *National Vital Statistics Reports* 64, no. 9 (2015), [https://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64\\_09.pdf](https://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_09.pdf) (accessed 08/23/2017).

<sup>17</sup>Ngui et al., 6.

infants in Milwaukee die more often than infants in Syria, Algeria, and Cuba. For a country with the largest Gross Domestic Product (GDP) in the world, *and* which spends the largest percentage of its GDP on health care, these statistics don't seem to match.<sup>18</sup> Put by a fellow attendee at a lecture about infant mortality, "If White people are sick, then Black people have pneumonia."<sup>19</sup> Undoubtedly parents have an integral role in ensuring the well-being of their children. However, when we know contributing factors are going on outside of parental control, social institutions must be held accountable, and communities need to take action.

To better understand why babies are dying, let us start by examining the categories for cause of infant death. According to data collected from 2012 to 2015, the most common cause of infant mortality is prematurity, which accounts for 55.6% of all infant deaths in Milwaukee. While the exact cause of prematurity in individual instances is difficult to determine, 20.8% have risk factors related to maternal health, such as infection, diabetes, or hypertension.<sup>20</sup> Other subcategories of risk factors for prematurity include placenta, cord or membrane infections; short gestation, low birth weight; complications of twin or triplet births; and complications of preterm birth (for example, sepsis and intraventricular hemorrhage). Separate from prematurity, congenital abnormalities and related complications make up an additional 15.9% of infant deaths in Milwaukee. Then, 15% of infant deaths fall under the category Sudden Infant Death Syndrome (SIDS), Sudden Unexplained Death in Infancy (SUDI), or accidental suffocation. This

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<sup>18</sup>The World Bank, "GDP Ranking," <https://data.worldbank.org/data-catalog/GDP-ranking-table> (accessed 08/23/2017); The World Bank, "Health Expenditure, Total (% of GDP)," <http://data.worldbank.org/indicator/SH.XPD.TOTL.ZS> (accessed 08/23/2017)

<sup>19</sup>Conference participant, Courage to Love Lecture, Chicago, IL, June 2017.

<sup>20</sup>*Ibid.*, 21.

category includes deaths attributed to unsafe sleep.<sup>21</sup> The remaining 7.6% are labeled as infant deaths caused by complications of labor and delivery, homicide, infection, or “other.”<sup>22</sup>

In some of these categories, Black mothers experienced higher instances of infant mortality than their counterparts of other racial/ethnic backgrounds.<sup>23</sup> For example, 60.7% of Black women experienced prematurity compared to 32.6% of White women.<sup>24</sup> In a previous report, looking at deaths from 2009 to 2011, the most drastic racial health disparity contributing disproportionately to Black infant deaths in Milwaukee was perinatal complications: during this time Black mothers experienced ten out of the eleven infant deaths caused by complications of labor and delivery.<sup>25</sup> Similarly, Black mothers experienced higher instances of stillbirth in all but one category.<sup>26</sup> From 2009-2011, out of all Black infants who died, 123 were due to complications of prematurity; 32 due to congenital abnormalities; and 30 due to SIDS, SUDI, and accidental suffocation. In addition, ten died due to perinatal complications; seven due to homicide; four due to infections, and three were labeled “other.”<sup>27</sup>

### **Intersections of Race, Class, and Gender**

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<sup>21</sup>Ibid.

<sup>22</sup>Ibid., 7.

<sup>23</sup>Complications of prematurity; congenital abnormalities; SIDS, SUDI, and accidental suffocation; perinatal complications, homicide, infections, and other FIMR, 20.

<sup>24</sup>Ibid., 14.

<sup>25</sup>Ibid., 21.

<sup>26</sup>Categories for causes of stillbirth include undetermined; maternal disease/infection; congenital anomalies; abruption; cord accident; placental insufficiency; incompetent cervix; trauma; homicide. The only category in which Black women did not have a higher instance of stillbirth than women of other races was Homicide. During the timeframe of the study, only one woman experienced stillbirth as a result of homicide, and she was Hispanic. FIMR, 10.

<sup>27</sup>FIMR, 20, 30.

While it is important for a pregnant woman to make healthy lifestyle choices, the choice for a healthy baby is by no means fully, or even mostly, within her grasp. Socioeconomic factors constrain choices available to pregnant women and parents, and disproportionately affect African American women and their birth outcomes. Indeed, race adds another layer, with the experience of structural racism being especially prevalent in the lives of Black women. The ways in which race, class, and gender disparities stack the deck against Black women will be discussed in the following sections, with particular attention to health effects during pregnancy. It is important to keep in mind that while no woman's situation can be summed up by a statistic, intersecting disparities based on class, race, and gender culminate to produce devastating effects for individual Black women and their infants.

### **Socioeconomic Disparity**

Social scientists have shown over and over again how poverty—and other related social markers like education, employment, access to health care, and housing—directly impact the health statuses of individuals and communities. These risk factors affect Black neighborhoods more so than White neighborhoods nationwide, and Milwaukee is no exception. In 2014, the poverty rate among African Americans in Milwaukee was 39.9%, compared to 31.8% among Hispanics and 14.8% among non-Hispanic Whites.<sup>28</sup> Research shows that areas of high poverty and income inequality are significantly associated with preterm birth.<sup>29</sup>

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<sup>28</sup>Bill Glauber and Kevin Crowe, "Poverty Keeps Tight Grip on Milwaukee, New Census Figures Show," *Milwaukee Journal Sentinel*, September 16, 2015, <http://www.jsonline.com/news/milwaukee/poverty-keeps-tight-grip-on-milwaukee-new-census-figures-show-b99578039z1-327971271.html> (accessed February 23, 2016).

<sup>29</sup>Maeve E. Wallace, et al., "Preterm Birth in the Context of Increasing Income Inequality," *Maternal and Child Health Journal* 20, no. 1 (January 2016): 164-171.

Lack of education, joblessness, inadequate access to health care, low homeownership, and unsafe neighborhoods compound the reality of being poor, and are related to poor birth outcomes. In Milwaukee, 18% of Black women and 22% of Black men lack a high school diploma or equivalent, compared to 7% of non-Hispanic White women and 6% of non-Hispanic White men.<sup>30</sup> Wisconsin has the highest rate of incarceration for Black men in the country, with more than half of all Black men in their 30s and 40s in Milwaukee having spent time in prison and away from their families.<sup>31</sup> Poverty and violence go hand in hand, and together, they create a vicious circle that is detrimental to health: both community violence and intimate partner violence are tied to chronic stress, which is a risk factor for premature birth and infant death.<sup>32</sup>

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<sup>30</sup>“Sex by Educational Attainment for the Population 25 Years and Over (Black or African American Alone),” 2014 American Community Survey 1-year Estimates, United States Census Bureau, [http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS\\_14\\_1YR\\_B15002B&prodType=table](http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_14_1YR_B15002B&prodType=table) (accessed February 23, 2016); “Sex by Educational Attainment for the Population 25 Years and Over (White Alone, Not Hispanic or Latino),” 2014 American Community Survey 1-Year Estimates, United States Census Bureau, [http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS\\_14\\_1YR\\_B15002H&prodType=table](http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_14_1YR_B15002H&prodType=table) (accessed February 23, 2016).

<sup>31</sup>John Pawasarat and Lois M. Quinn, “Wisconsin’s Mass Incarceration of African American Males: Workforce Challenges for 2013,” Employment and Training Institute, University of Wisconsin-Milwaukee, 2013, <http://www4.uwm.edu/eti/2013/BlackImprisonment.pdf> (accessed September 16, 2016).

<sup>32</sup>Robert J. Kane, “The Ecology of Unhealthy Places: Violence, Birthweight, and the Importance of Territoriality in Structurally Disadvantaged Communities,” *Social Science and Medicine* 73, no. 11 (December 2011): 1585-1592; Jeanne L. Alhusen et al., “Intimate Partner Violence During Pregnancy and Adverse Neonatal Outcomes in Low-Income Women,” *Journal of Women’s Health* 23, no. 11 (November 2014): 920-926; G. Latendresse, “The Interaction Between Chronic Stress and Pregnancy: Preterm Birth From a Biobehavioral Perspective,” *Journal of Midwifery and Women’s Health* 54, no. 1 (January 2009): 8-17.

We also know that birth weight increases and infant death decreases with maternal education,<sup>33</sup> and that family social support is a key indicator for healthy pregnancies.<sup>34</sup>

Black families in Milwaukee shoulder more of the burdens of poverty than their White and Hispanic counterparts. These racial disparities ought to be a key area of concern for Milwaukee, which, according to 2010 US census data, is tied with Detroit as the most Black-White segregated city in the country.<sup>35</sup> While poverty and associated social conditions affect the health statuses of all women, they affect Black women to a more significant degree than other racial/ethnic groups. These examples show that while poverty is detrimental to birth outcomes for women of all racial/ethnic backgrounds, they are significantly more severe if you are a Black woman.

### **Racial Disparity and White Privilege**

What happens when we compare infant mortality rates for Black and White women with similar socioeconomic statuses? Surely well-educated, employed, insured and home-owning Black women ought to have the same birth outcomes as their White and Hispanic counterparts. Shockingly, this is not the case. Consider that the infant mortality rate for college-educated Black

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<sup>33</sup>R. Din-Dzietham and I. Hertz-Picciotto, "Infant Mortality Differences between Whites and African Americans: The Effect of Maternal Education," *American Journal of Public Health* 88, no. 4 (1998): 651-656; although infant mortality has been reported to increase at very high levels of maternal education (e.g., more than 16 years of education). I. Shoham-Yakubovich and V. Barel, "Maternal Education as a Modifier of the Association between Low Birthweight and Infant Mortality," *International Journal of Epidemiology* 17 (1988): 370-377.

<sup>34</sup>Anne Dunlop et al., "Interpregnancy Primary Care and Social Support for African-American Women at Risk for Recurrent Very-low-birthweight Delivery: A Pilot Evaluation," *Maternal and Child Health Journal* 12, no. 4 (July 2008): 461-468.

<sup>35</sup>John R. Logan and Brian J. Stults, "The Persistence of Segregation in the Metropolis: New Findings from the 2010 Census," Census Brief prepared for Project US2010, <http://www.s4.brown.edu/us2010/Projects/Reports.htm> (accessed February 23, 2016).



women in the United States is 2.4 times higher than for similarly educated White women.<sup>36</sup> In fact, White women *who haven't finished high school* experience a lower rate of infant mortality than *college-educated* African American women.<sup>37</sup> Therefore, even when socioeconomic factors are controlled for, race persists as a statistically significant risk factor for infant stillbirth and death.

What is driving this disparity? One factor is stress. Stress can be caused by a myriad of life events, including having a child, losing a job, or the death of a loved one. Stressors can be related to environment: violence, unstable housing, and lack of access to good health care or child care, for example. Stress can also be caused by the experience of racial discrimination throughout the course of one's life. One study found that African American women felt that their experiences of stress and racism negatively impacted their pregnancies.<sup>38</sup> Another study based on focus groups and interviews with Black women in Milwaukee found that participants perceived discriminatory treatment in their prenatal care based on three different categories: insurance or income status, race, and lifetime experiences of racial discrimination.<sup>39</sup> Indeed, when life event stressors affect someone of a racial minority group, they may be exacerbated by underlying,

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<sup>36</sup>United States Department of Health and Human Services, Centers of Disease Control and Prevention, National Center for Health Statistics, Division of Vital Statistics. Linked Birth / Infant Death Records 2007-2016, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program, on CDC WONDER On-line Database, <http://wonder.cdc.gov/lbd-current.html> on (accessed January 7, 2019).

<sup>37</sup>Ibid.

<sup>38</sup>Glenna Barnes, "Perspectives of African-American Women on Infant Mortality," *Social Work in Health Care* 47, no. 3 (2008): 293-305.

<sup>39</sup>Trina Salm Ward et al., "'You Learn to Go Last': Perceptions of Prenatal Care Experiences Among African-American Women with Limited Incomes," *Journal of Maternal and Child Health* 17 (2013): 1753-1759.

constant stress due to experiences of racism. And stress is not just a social and emotional feeling—it has physiological effects that are detrimental to overall health.

A growing body of research is linking stress to premature births. Scholars who take a life-course approach to maternal-fetal wellness hold that stress spanning one's lifetime—including stress related to or caused by racial discrimination—can manifest in physiological symptoms that can contribute to pre-term birth.<sup>40</sup> The terms “allostatic load burden” and “weathering” are used to describe the cumulative effect social and economic disadvantages across generations have on Black women that cannot be accounted for by any other factor than race.<sup>41</sup> Consider a recent study that found statistically significant differences in placental telomere length.<sup>42</sup> Telomeres are important for protecting chromosomes and are vital for healthy cell division and overall cell health. Black women were found to have shorter placental telomeres. Having shorter telomeres is associated with rupture of the amniotic sac, onset of labor, and parturition—all risk factors for prematurity. The cause of shorter telomeres? Accelerated cellular aging, which is an effect of traumatic stress. Stress is important to pay attention to: pregnant, well-educated African American women who report experiencing stress in general, as well as stress specifically related to gender and race, are more likely to experience depression, which is a risk factor for poor birth

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<sup>40</sup>Michael Lu et al., “Closing the Black-White Gap in Birth Outcomes: A Life-Course Approach,” *Ethnicity and Disease* 20 (2010): s2-62-s2-76; Cheryl L Giscombé and Marci Lobel, “Explaining Disproportionately High Rates of Adverse Birth Outcomes among African Americans: The Impact of Stress, Racism, and Related Factors in Pregnancy,” *Psychological Bulletin* 131, no. 5 (2005): 662-683.

<sup>41</sup>A. Geronimus et al., “‘Weathering’ and Age Patterns of Allostatic Load Scores among Blacks and Whites in the United States,” *American Journal of Public Health* 96, no. 5 (2006).

<sup>42</sup>C.W. Jones et al., “Differences in Placental Telomere Length Suggest a Link between Racial Disparities in Birth Outcomes and Cellular Aging,” *American Journal of Obstetrics and Gynecology* (March 2017): 294.e4.

outcomes.<sup>43</sup> This study shows that being a Black woman in the US has consequences so far reaching that development at the cellular level is affected.

Stress is an important factor that contributes to allostatic load burden, among other physical and psychosocial markers that are intertwined. Studies show that chronic exposure to poverty, discrimination, and racism cause chronic stress that manifests in physiological symptoms—including elevated cortisol levels and coronary artery calcification—that have negative effects on health and pregnancy.<sup>44</sup> Chronically elevated cortisol levels caused by increased stress throughout life may lead to a compounding of the normal immune suppression that occurs during pregnancy, resulting in a heightened risk for prematurity and infant death.<sup>45</sup>

Hypertension, or chronically high blood pressure, is another physiological symptom related to stress. Black men and women in Chicago and Cape Town, South Africa have disproportionately higher blood pressures than those in Seychelles, Kingston, Jamaica, and rural Ghana. The researchers who found these outcomes conclude that while it is possible that differences in diet may contribute to higher blood pressure, “one potential explanation of this finding could be the deleterious effect of social discrimination that is a prominent feature of both

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<sup>43</sup>Fleda M. Jackson et al., “Contextualized Stress, Global Stress, and Depression in Well-Educated African American Women,” *Women's Health Issues Journal* 22, no. 13 (May-June): e329-e336.

<sup>44</sup>Tyan Parker Dominguez et al., “Racial Differences in Birth Outcomes: The Role of General, Pregnancy, and Racism Stress,” *Health Psychology* 27, no. 2 (2008): 194-203. T. Lewis, et al., “Chronic Exposure to Everyday Discrimination and Coronary Artery Calcification in African-American Women: The SWAN Heart Study,” *Psychosomatic Medicine* 68, no. 3 (2006): 362-368; Geronimus et al., 826-833; C. Hilmert et al., “Lifetime Racism and Blood Pressure Changes during Pregnancy: Implications for Fetal Growth,” *Health Psychology* 33, no. 1 (2014): 43-51.

<sup>45</sup>G.P. Chrousos, “The Stress Response and Immune Function: Clinical Implications,” The 1999 Novera H. Spector Lecture, *Annals NY Academy of Science* (2000) 917: 38-67.

US and South African society.”<sup>46</sup> Given the body of research describing how nutritional practices of African Americans are affected by cultural practices rooted in food scarcity during slavery, residential segregation, and race-targeted food product advertising, it is important for findings like these to be contextualized within the racialized history of the US.<sup>47</sup> Indeed, what the United States and South Africa have in common that is lacking in the other countries is the presence of racial segregation and a history of social class hierarchy founded on racial discrimination. Another example of the historical embeddedness of racial discrimination is presented by a study that shows the correlation of Jim Crow laws with higher infant death rates among southern African Americans today.<sup>48</sup> These realities point out how racialized experiences are embedded in social determinants of health to the disadvantage of those with darker skin.

In the United States, White privilege flourishes in direct relationship with Black communities’ experiences of racial injustice. One description of White privilege offered by theologian and social ethicist Bryan Massingale is “the uneven and unfair distribution of power, privilege, land, and material resources favoring White people.”<sup>49</sup> He points out that while a key component of White culture is the presumption of dominance and entitlement, the corresponding

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<sup>46</sup>Ibid., 9.

<sup>47</sup>Peter Riley Bahr, “Race and Nutrition: An Investigation of Black-White Differences in Health-Related Nutritional Behaviours,” *Sociology of Health and Illness* 29, no. 6 (2007): 831-856.

<sup>48</sup>This study suggests that analysis of social determinants of health needs to take into account how public policy in particular areas may affect racial disparities in infant mortality. Nancy Krieger et al., “The Unique Impact of Abolition of Jim Crow Laws on Reducing Inequities in Infant Death Rates and Implications For Choice of Comparison Groups in Analyzing Societal Determinants of Health,” *American Journal of Public Health* 103, no. 12 (2013): 2234-2244.

<sup>49</sup>Bryan Massingale, *Racial Justice and the Catholic Church* (Maryknoll: Orbis Books, 2010), 40-41.

key component of Black culture is the expectation of struggle.<sup>50</sup> In communities where African Americans have been systematically disenfranchised from opportunities that White people were given historically, White people are given certain advantages that are not afforded to their brown-skinned counterparts. This understanding of White privilege helps explain why in Milwaukee, when manufacturing jobs dried up in the 1980's, many White families had enough resources to cut their losses and head for the suburbs while many Black homeowners, some whose early years spent in the Jim Crow South negated any opportunity for wealth accumulation, were stuck in mortgages now more costly than what their homes were worth.<sup>51</sup> White privilege will be discussed more in depth in Chapters Four and Five.

### **Constraints on Moral Agency**

Maternal health and lifestyle choices are often complicated by factors that are not solely within a woman's control. Women are encouraged to increase their chances of having healthy babies by practicing habits that limit risk factors for prematurity. Healthy eating, exercise, actively managing chronic health conditions, avoiding alcohol and cigarette smoke, and taking folic acid supplements all increase the likelihood of having a healthy, full term baby.<sup>52</sup> Conversely, obesity, smoking, close interval pregnancy, alcohol use, unsafe sleep, late or no prenatal care, chronic hypertension, and diabetes (type I, II, and gestational) all correlate with

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<sup>50</sup>Ibid., 24. Citing Roy L. Brooks and Ruth Frankenberg.

<sup>51</sup>James E. Causey, "Homeownership has not Delivered on the American Dream for African Americans," *Milwaukee Journal Sentinel* (April 27, 2017), <https://projects.jsonline.com/news/2017/4/27/for-african-americans-homeownership-has-not-delivered-dreams.html> (accessed 08/23/2017).

<sup>52</sup>Centers for Disease Control and Prevention, "Planning for Pregnancy," <http://www.cdc.gov/preconception/planning.html> (accessed May 9, 2016). CDC, "During Pregnancy," <http://www.cdc.gov/pregnancy/during.html> (accessed May 9, 2016).

worse outcomes for infants.<sup>53</sup> Women can, to some degree, engage in these healthy behaviors and mitigate unhealthy ones. However, the vast majority of infant deaths cannot be explained by a parent's bad choices.

Though it is clear that complications of prematurity is the most common cause of infant deaths in Milwaukee, much attention is placed on reducing deaths caused by SIDS, SUDI, and accidental suffocation. In response, many initiatives to address infant mortality focus on parental behavior related to individual health and infant care practices. For example, infant safe sleep is presented as a “low hanging fruit” that can be adequately addressed through teaching the ABCS of safe sleep and providing new moms with cribs or other safe places for infants to sleep. Spreading the message that infants sleep safest Alone, on their Back, in a Crib, and in a Smoke-free environment is thought to be an easy and effective means of keeping babies safe through modifying parent behavior. Media stories about causes of infant death disproportionately focus on accidental suffocation deaths instead of prematurity—especially those involving co-sleeping in predominantly African American neighborhoods.

For example, a January 2018 *Milwaukee Journal Sentinel* article grossly misrepresents the facts by stating “[m]ore than half of all infant deaths in Milwaukee County last year were related to an unsafe sleep environment.” This statement is flat out false, given the data showing prematurity to be the leading cause of infant death. The article continues by reporting that the medical examiner's office investigated 45 infant deaths, finding 25 were related to unsafe sleep

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<sup>53</sup>Ibid.; FIMR, 13.

environments, which include co-sleeping, sleeping in an adult bed or with pillows and toys.”<sup>54</sup>

While this statement is factual, it misses the reality that most infant deaths are not investigated by the medical examiner’s office, and occur in the hospital. The article also reports specifics about the first infant death of 2018, noting that it occurred in a home on the city’s northwest side. Milwaukee residents are keenly aware that predominantly African American families live in this area. Additionally, the media disproportionately reports on Black infant sleep-related deaths when compared to White infant sleep-related deaths, and even when race is not explicitly named, neighborhoods and zip codes are often used as a stand-in for race in Milwaukee.<sup>55</sup>

In her critique of the biopolitics of Milwaukee’s infant mortality reduction campaign from 2010-2013, White geographer Kristin Sziarto notes the radical disconnect between the data showing prematurity to be the leading cause of infant death and the disproportionate focus placed on the sleep-related deaths of Black infants. Sziarto contends:

The campaign assembled a range of biopolitical logics and practices that through the lenses of race and space, can be seen to be contradictory. On one hand, they located the problem of the “racial gap” in segregated neighborhoods-in-crisis, and scanted publicity on the systemic nature of infant mortality. On the other hand, the “safe sleep” campaign, built on public health models of health beliefs and media and marketing agencies’ commitment to shocking images, was “race-blind” in positing White and Black babies in equivalent danger. This campaign, using images of babies in danger to generate consensus and forestall criticism of racial partiality, both drew criticism, and failed to prevent blaming of parents, especially Black parents.<sup>56</sup>

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<sup>54</sup>Ashley Luthern, “Medical Examiner: Half of Infant Deaths in Milwaukee County in 2017 Related to Unsafe Sleep,” *Milwaukee Journal Sentinel* (January 2, 2018), <https://www.jsonline.com/story/news/local/milwaukee/2018/01/02/medical-examiner-half-infant-deaths-milwaukee-county-2017-related-unsafe-sleep/996044001/> (accessed September 12, 2018).

<sup>55</sup>Kristin Sziarto, “Whose Reproductive Futures? Race-Biopolitics and Resistance in the Black Infant Mortality Reduction Campaigns in Milwaukee,” *Society and Space* 35, no. 2 (2017): 307-308.

<sup>56</sup>*Ibid.*, 314.

The ad campaign Sziarto refers to showed an infant sleeping in an adult bed with pillows, a comforter (both risk factors for accidental suffocation), and a kitchen knife (as a symbol of the mortal danger posed by the adult body). Two versions were made, one with a Black infant, the other with a White infant. Sziarto notes that “[l]ocal Black leaders and others criticized the campaign for communicating an unclear message, blaming, and shaming of Black parents, and neglect of the voices of the Black community,” including Black focus group participants who were not listened to when they voiced the ad’s confusing message to the marketing company.<sup>57</sup> Billboard images of infants sleeping in beds with knives coupled with a narrative that Black neighborhoods are unsafe for babies is not only a gross misrepresentation of the facts, but irresponsibly and unjustly places the blame at the feet of Black parents. Sziarto concludes that what is needed is a “bipolitical solidarity around infant mortality” that can “draw on ethics of care, and lead to policy enacting compassion for parents, alongside anti-racist work with medical professionals.”<sup>58</sup>

We must acknowledge that racism plays a strong contributing role to infant mortality, and therefore a focus on parental behavior is not only irresponsible, but unjust. Indeed, it is apparent that having a healthy baby is not entirely within the agency of women: especially Black women, and especially in Milwaukee. Therefore, our community cannot just blame women for being “bad,” “irresponsible” mothers in instances of infant stillbirth and death when we know that social determinants of health loom large. Public health practices cannot then focus solely on modifying the behaviors of pregnant women and parents of infants. A woman’s choices and

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<sup>57</sup>Ibid., 311.

<sup>58</sup>Ibid., 315.



behaviors alone are not direct determinants of birth outcomes. This is especially important when considering communities of color, who have so often throughout history been portrayed as morally corrupt.<sup>59</sup> This realization means we need to move beyond advocating for individual lifestyle practices that lead to healthy infants.

“Something’s not right.” I’ve heard Mary’s sentiment echoed many times by people working to reduce infant mortality in Milwaukee. After sharing these same words, a researcher opined that there is something about “the unique experience of being Black in America” that is bad for Black mothers and their babies. To better understand what is meant by these words, consider this case study published in the local newspaper. It helps shine a spotlight on how socioeconomic and racial/ethnic disparities affect women and infants in Milwaukee.

### **An Alternative Narrative: Baby Zyon**

Tia Love gave birth to her first child, a boy she named Zyon, on Sept. 14, 2011. Love... is African-American and lives in a predominantly African-American neighborhood on the city's near north side. She knew the statistics: In Milwaukee, Black babies die during their first year of life at three times the rate of White babies. "I was terrified," Love said recently. "I wanted him to be a natural healthy baby."

Premature birth is the leading cause of infant mortality in Milwaukee. Stress increases the risk of premature births. And Love had more than her share of stressors. Single. No job. Her mother in prison and little more than a vague memory. Her father, who raised her, hospitalized and dying. "I didn't know how to be a mom," she said. "I barely knew how to be a woman." Love couldn't sleep. She was always sick. She developed pre-eclampsia, a leading cause of prematurity.

Love's doctor put her in touch with the Milwaukee Health Department, and there Love met Erin Cronn, one of nine public health nurses in the department's Nurse-Family Partnership, an intensive home visitation program serving low-income, first-time pregnant women living in 11 high-risk ZIP codes. "Tia had a lot going on," Cronn said. "She was just so overwhelmed." "I told her: "Tia, you're fine. You just don't know it yet."

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<sup>59</sup>For example, women whose children differ from the so-called “norm” of healthy, White, breastfed, and cared-for-by-mom-at-home are deemed “bad mothers.” Amy Laura Hall, *Conceiving Parenthood: American Protestantism and the Spirit of Reproduction* (Grand Rapids: Eerdmans Publishing Company, 2007).

Cronn visited Love every week for four weeks, then every two weeks until Zyon was born - nine days before his due date, but weighing a healthy 7 pounds, 9 ounces - then every week for six weeks. Cronn will continue to visit Love every two weeks until Zyon turns 2.

Her place in their lives is more than medicinal. She is a mentor, a therapist, a sociologist, a dietitian and a friend. Those things are important because becoming the parent of a healthy child requires more than biological readiness. An effective response to infant mortality must also address the social determinants of maternal and child health: It must address those issues long before a woman becomes pregnant, and it must address those from one generation to the next. Smoking is bad for the unborn. So is poverty. So is racism. Love put it this way: “There is no separation between a woman's environment and her womb.”<sup>60</sup>

This story offers an example of how a different relationship between Black women and community partners like the health department, health care systems, and churches can be formed if practices rooted in justice, solidarity, and respect are prioritized. Why isn't this approach to caring for women and infants the norm? It is my suspicion that a lack of understanding of the root causes of infant mortality disparities has led to apathy for Black women and their children. A reframing of the situation as an injustice of refused solidarity with Black women and families is an important starting point to correct this unwarranted disposition. As German Catholic moral theologian Hille Haker posits, solidarity has the potential to prioritize “transformative justice that keeps awake the memory of the pain and outrage about injustice and, supported by the moral emotion of compassion, disposes moral agents to take steps toward transforming injustice to justice.”<sup>61</sup> In this way, justice is not only concerned with the redistribution of resources, but in

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<sup>60</sup>Excerpt from Crocker Stephenson, “Program to Reduce Infant Mortality Slow to Get Going,” *Milwaukee Journal Sentinel* (February 13, 2016), <http://www.jsonline.com/news/milwaukee/programtoreduceinfantmortality-slowtogetgoingr68pjvo191558341.html> (accessed June 10, 2015). Reformatted from the original.

<sup>61</sup>Hille Haker, “Compassion for Justice,” *Concilium* (2017): 4.

transforming social structures and relationships that currently disrespect and disempower Black women and families.

While we should celebrate that Love's son was born healthy, we also must wrestle with the fact that Love and her child are the lucky ones. Many of her peers—including women you will meet in Chapter Three—face the same social determinants of health and end up suffering the loss of a baby. This vignette exemplifies how systemic issues related to socioeconomic and racial inequality are at play in the lives of Milwaukee's Black women, infants, and their families. Unfortunately, the racial disparity between Black and White infant mortality mentioned in this article has stubbornly persisted for over 10 years in Milwaukee. This stagnation begs investigation into the methods and practices used by various community partners: health care systems, governmental agencies, community organizations, and most recently, churches. What is it about Milwaukee that allows this racial health disparity for Black infants to persist? Is there something in the water? In all seriousness, it is apparent that there is something about the cultural milieu of Milwaukee—its history, people, values, institutions—that is unhealthy for Black women and their babies.

Even more, what should be done to correct this race-based disparity? In countries where the median income is much lower than in the United States, strategies like increasing early education for girls and addressing income disparities have been shown to be promising for reducing infant mortality. However, these initiatives only go so far, and in the United States focusing on education and income do not change the racial disparity in infant mortality: recall that despite their college education, Black women experience infant death more often than White

women who haven't finished high school.<sup>62</sup> Therefore the answer cannot be initiatives that address socioeconomic factors alone. We need to think creatively about how to identify and correct the imbalances caused by the dynamic of racism and privilege. One key strategy may be reducing interpersonal and structural racism that is manifest in the everyday social interactions of Black women. Integral to this strategy would be to invite those who benefit from White privilege to confront it.

The Milwaukee Health Department acknowledges that while focusing on individual behavior is important, there is more work to do to address infant mortality. In a 2016 press release, it identifies three main areas essential for addressing Milwaukee's birth outcomes: 1) improve individual behaviors; 2) improve access to quality medical care; and 3) reduce lifecourse stressors. This briefing goes on to state, "It's important to keep in mind that there is no ONE most important thing. Infant Mortality, and healthy birth outcomes generally, have multiple drivers, and addressing any one of them is simultaneously necessary and insufficient."<sup>63</sup> Then, each of these three areas is broken down into examples of specific objectives. To improve individual behaviors, objectives include early prenatal care, smoking cessation, safe sleep, and appropriate car-seats. Improving access to quality healthcare includes ensuring accessible hours without delays for prenatal visits and routine screenings for infection and chronic diseases for pregnant women. The initiative to reduce lifecourse stressors includes the most examples, and

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<sup>62</sup>Schell, C.O. et al., "Socioeconomic Determinants of Infant Mortality: A Worldwide Study of 152 Low-, Middle-, and High-Income Countries," *Scandinavian Journal of Public Health* 35, no. 3 (2007).

<sup>63</sup>City of Milwaukee Health Department, "City of Milwaukee 2015 Infant Mortality Rate (IMR): Data Brief (June 14, 2016), <http://city.milwaukee.gov/ImageLibrary/Groups/healthAuthors/MCH/PDFs/InfantMortality/2015IMRDataBrief20160614-ReleasedVersion.pdf> (accessed 08/23/2017). Capitalization is original.

ranges from objectives that address poverty and health insurance, to educational attainment and fatherhood involvement, to access to healthy foods and quality child care.

What is not included in this list of objectives addressing socioeconomic determinants of health is one that addresses personal and institutional racism in Milwaukee. However, this does not mean that the Milwaukee Health Department does not acknowledge racism as a contributing factor to racial health disparities in infant mortality. Presentations given by Milwaukee's former health commissioner and mayor have named racism in itself as a plight on our community. So why didn't it make the list? Naming racism as a foundational and pernicious factor contributing to infant mortality is a necessary paradigm shift, with the possibility to change the way risk factors for prematurity and infant mortality are categorized and how practices to mitigate them are developed. To help support this paradigm shift, a reframing of the ethical problem of infant mortality as a significant racial justice issue will be necessary, and forging paths toward interracial solidarity will be key. The concern for the lives of Black infants must be intrinsically linked with a concern for the dignity and equal regard for Black women. These connections will be expanded more in Chapter Five.

It is interesting to consider Baby Zyon's namesake from the vignette above. In the Hebrew Bible, Zion means both the physical city of Jerusalem as well as, in a spiritual sense, the City of God. How would we treat pregnant women and new families in the City of God? The answer must be multi-faceted. Programs aimed narrowly at educating pregnant women and new parents will not suffice. Practices for addressing poverty, racism, and barriers to health must be part of the answer. In addition, supportive relationships are key to preparing for and welcoming a new baby. The experience of struggling with how to be a woman and a mother, though

compounded by inequalities, is not unique to high-risk zip codes. As a new mother myself, these challenges resonate with me, and from personal experience I know they are best dealt with in community rather than alone.

Despite public health practices targeting individual behavior, access to primary, prenatal, and infant health care, and social determinants of health, the gap between Black and White infant deaths continues to grow in communities across our country. Though this reality seems surprising, it is not unique to present day Milwaukee. In 1984, a Pittsburgh commission on infant mortality considered the relationship between public health practices and birth outcomes.

Consider pediatrician and faith leader Ronald David's remarks:

Healthy pregnancy outcomes have little to do with access to health care. Moreover... contrary to conventional wisdom, poor pregnancy outcomes could not be attributed initially or primarily to ignorant, immoral, or responsible maternal behavior. I want to repeat that slowly, deliberately, and succinctly: Poor pregnancy outcomes and infant mortality are not a consequence of poor prenatal care or mothers behaving badly.<sup>64</sup>

David goes on to describe the integral role healthy relationships play in healthy births:

Now, lest your minds race to images and fantasies of the dysfunctional Black family let me hasten to clarify that the relationships about which the Commission speaks includes, but greatly transcend, domestic relationships. Indeed, it is the Commission's belief that domestic relationships are affected and infected by the culturally and socially toxic experiences of racism, misogyny and its attendant sexism, and income inequality that is itself a pale proxy for social inequalities more generally. These tears in the fabric of relationships are what make childbearing and child rearing such hazardous travails.<sup>65</sup>

To take these beliefs seriously would mean a reprioritization of public health practices, as well as a call to investigate new practices that can effectively mitigate racism, misogyny and sexism, and social inequalities writ large. There is no doubt that an adequate response will necessitate

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<sup>64</sup>Ronald David, "Go to Ruth's House: A Response to Infant Mortality," *BIRTH* 35, no. 2 (June 2008): 89.

<sup>65</sup>*Ibid.*, 90.

multiple engaged and willing partners with varying areas of expertise. What might it mean to respond to this call as a Christian? As a White woman? As a community partner? These questions provide a particular social location for my project. One response by people of faith has been the Strong Baby Sanctuary program.

### **The Strong Baby Sanctuary Program: A Brief Introduction**

A Catholic Health System, churches, and community organizations have joined forces with the Milwaukee Health Department to confront infant mortality in Milwaukee and the enmeshed racial disparities. This collaborative is co-founded by parish nurse Mary Evans and is based on her twenty year history of facilitating support groups for pregnant women and new mother. Their efforts began in 2011, when an inner-city Church of God in Christ elder partnered with a Catholic health system and the Milwaukee Health Department to name the second Sunday in October as a “Safe Sleep Sabbath.” More than 50 pastors attended an informational session to learn about infant safe sleep practices and were encouraged to spread the message about safe sleep from the pulpit. Since then, this partnership has grown to include the General Baptist State Convention of Wisconsin as well as churches of other Christian denominations in Milwaukee. Non-religious community organizations have also become part of the Strong Baby Sanctuary program steering committee, including the March of Dimes, the Life Course Initiative for Healthy Families, and the University of Milwaukee Maternal and Child Health Training Programs.

The model for intervention has also morphed: instead of focusing narrowly on safe sleep, pastors are now encouraged to preach about strong babies, each year focusing on a topic related to infant death. Past topics have included prematurity, stress and violence, and the importance of

early prenatal care. Strong Baby Sabbath has become the day to celebrate year-round work being undertaken by Strong Baby Sanctuaries: churches who have committed themselves to connecting pregnant women and families of infants to community resources. Guided by the mantra “strong babies, strong families, strong communities,” the Strong Baby Sanctuary program aims to “embrace pregnant women and their families and offer information and resources, mentorship and spiritual support to create stronger babies in the Milwaukee community.”<sup>66</sup> 2015 marked the launch of the Strong Baby Sanctuary program, when ten churches supported church members to go through specialized training to help pregnant women and new families’ access health care, food and housing resources, social support services, and religious community.

Now, 35 churches across Milwaukee identify as Strong Baby Sanctuaries. Volunteers from each church go through an orientation process which includes education on how to connect women and their families to resources in the community for health care, food, infant needs, and spiritual support. The steering committee also puts on educational programming for volunteers four times a year. Topics have included strategies for managing stress, prenatal care coordination services and home visitation resources, and bereavement for those who have experienced loss. Steering committee members emphasize that the role of the Strong Baby Sanctuary volunteer is not to be the expert or have all the answers, but to know how to connect women to resources and walk with them to meet their needs. Strong Baby Sanctuary volunteers use a standard intake form that helps ensure basic needs are being met. Strong Baby Sanctuaries commit to providing these services at a base level.

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<sup>66</sup>Columbia St. Mary’s, “Strong Baby Sanctuary,” [http://www.columbia-stmarys.org/Strong\\_Baby\\_Sanctuary](http://www.columbia-stmarys.org/Strong_Baby_Sanctuary) (accessed 07/26/2017).



In addition, out of the 35 sanctuaries, 12 hold regular support groups for pregnant women and new families. Centered around a meal, pregnant women and families of infants meet with church volunteers and public health nurses to share health education and offer social and spiritual support. Groups meet weekly or monthly depending on the church. Endearingly named “Blanket of Love” groups, this branch of the program is modeled after a program started in 2004 by Mary Evans, the parish nurse with the Catholic health system. Since then, over 300 healthy infants have been born by women in that program with no infant deaths. This program shows incredible promise for offering that missing piece of social and spiritual support.

Along with the opportunity for the Strong Baby Sanctuary program to positively affect the lives of Milwaukee’s infants, mothers, and families—especially those who endure the injustices of socioeconomic and racial/ethnic disparity—come certain challenges. Secular partners recognize the importance of spiritual support, but question how churches can deliver effective messages about family planning practices, sex before marriage, and single motherhood. Churches want to ensure their programs bring something unique to the table instead of offering a limited version of a public health program. These concerns are important to consider as this program grows. We owe it to Milwaukee’s babies to collaborate, play to our respective strengths, and come together with the best possible strategies to effectively eliminate racial disparities in infant mortality. The next chapter will address how this project specifically is a work in theology and ethics, and introduces how the joint methods of Christian bioethics and ethnography can inform a response to this inquiry.

This has been an introduction to the problem of infant mortality and the particular devastation premature birth and infant death has in the lives of Black women in Milwaukee. One

main argument of this dissertation is that listening to Black women and those health care providers and volunteers who are closest to the problem is a necessary step for re-evaluating the situation and possible responses. Before turning to the voices of the collaborators to this project for their insights in Chapters Three and Four, the following chapter discusses the adequacy of some frameworks, principles, and methods for a Christian bioethic that can be attentive to the intersecting realities of race, class, and gender that complicate infant mortality. Chapter Two explores current frameworks in bioethics and offers some critique for how US bioethics can more adequately respond to the crisis in infant mortality. This next chapter also introduces ethnography as a fitting partner for a Christian bioethical approach to this problem.

## CHAPTER TWO

### ETHICAL APPROACHES TO RESPONDING TO THE INFANT MORALITY CRISIS

The current disparity in infant mortality between Black infants and their counterparts of other racial backgrounds is widely viewed as a social injustice by scholars working across numerous fields. Medical sociologists, physicians, midwives, social workers, and researchers in public health address this problem and propose solutions.<sup>1</sup> This project is in dialogue with these fields, and seeks to complement their work. Specifically, what I hope to contribute through this chapter's analysis is threefold: First, I propose that the kind of attention to social vulnerabilities like race, class, and gender that is necessary to adequately address the moral issues raised by infant mortality rates is currently missing in mainstream bioethical reflection. Next, I suggest how Christian bioethics can make real contributions in terms of ethical analysis and recommendations for action. Third, I offer that ethnography as incorporated into Christian bioethics is a fitting way to engage deeply in ethical issues related to maternal and infant health.

Accordingly, this chapter unfolds in three parts. First it considers what the field of bioethics may bring to bear on the problem of racial disparities in infant mortality as laid out in Chapter One. This section includes a critique of principlism, the most common methodological approach in US bioethics, as well as a case study that exemplifies the limits of a common application of this approach as it relates to infant health.<sup>2</sup> Next I advocate for a contextualized

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<sup>1</sup>See footnotes from discussions of socioeconomic and racial health disparities in Chapter One.

<sup>2</sup>As will be discussed further, principlism refers to the framework for bioethical deliberation that proposes balancing four core mid-level principles (respect for autonomy, beneficence, nonmaleficence, and justice) to help

approach to justice in bioethics. This approach will include reframing bioethics through the lens of African American scholarship on race, class, and gender, and then through the lens of Christian ethics. From this discussion, I develop specific commitments that ground my approach to infant mortality, including ethnography as a fitting method for bioethics. Then this chapter carves out specific commitments that ground a Christian bioethical approach to this issue. Finally, it offers up ethnography as a fitting methodological partner for doing this kind of work, and a description of the study I designed based on these central commitments and method.

### **Infant Mortality and Bioethics**

Bioethicists have an important voice to contribute to dialogue about reducing infant mortality. Sociologist John Evans explains that bioethicists engage in professional activity in four distinct spheres: healthcare ethics consultation, public policy bioethics, research bioethics, and cultural bioethics.<sup>3</sup> The contributions of bioethicists to moral reflection and action related to infant mortality can be imagined to take place in each of these spheres. Examples may include consulting with health care providers about approaches to prenatal care; analyzing public health efforts to reduce infant mortality; setting research agendas related to prenatal care; and prompting discussion and action among community members who hold common religious, cultural, or communal values that are related to infant and maternal health.

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guide analysis and responses to ethical questions. The most prominent description of this model is promulgated by Tom Beauchamp and James Childress, and it is widely used in bioethical deliberation in medicine and health care.

<sup>3</sup>John Evans, *The History and Future of Bioethics: A Sociological View* (Oxford: Oxford University Press, 2012), xxviii-xxxiii.

While bioethicists can be formally trained in medicine, theology, philosophy, law, sociology, or other related fields, they are bound together by a common activity. Evans describes bioethicists as:

professionals who use methods in a system of abstract knowledge wherein ethical recommendations are *not* based on their own personal values or the values of a particular group in society, but based on the values of either the individuals involved with an ethical decision or the values of the entire public.<sup>4</sup>

Evans also references bioethicist and law professor R. Alto Charo's view that a distinctive feature of the bioethicist's role is a "commitment to analytical reasoning that helps others to articulate their assumptions and fundamental values and challenges others to develop positions that logically flow from those assumptions and values."<sup>5</sup> From these descriptions, and the examples of the likely activities of bioethicists above, I offer that a constructive role bioethicists can play in response to infant mortality would be to gather and elucidate the values held by diverse groups within a community about infant and maternal health, bring these values to bear on the facts surrounding racial disparities in infant mortality, and promote ethical recommendations and actions that logically flow from these values.<sup>6</sup>

In addition, I argue that bioethicists ought to play a role in responding to the infant mortality crisis by calling attention to how social power dynamics are influenced by the institutionalized racism that pervades our social and medical institutions, public policy, and

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<sup>4</sup>Emphasis original. Ibid., xxi.

<sup>5</sup>R. Alto Charo, "The Endarkenment," (95-107), in *The Ethics of Bioethics: Mapping the Moral Landscape* eds. L.A. Eckenwiler and F.G. Cohn (Baltimore: The Johns Hopkins University Press, 2007), 98.

<sup>6</sup>While values normative to Western bioethics, like respect for autonomy, may be important to the situation of infant mortality, these values are by no means the only ones that matter. Listening to the diversity of value systems among community members who are both affected by infant mortality and in situations of power to respond to this crisis is immensely important to the work of bioethicists concerned with infant mortality.

community culture. Bioethicists can do this by unveiling hidden values and stereotypes concealed by implicit bias and help delineate how these values are at odds with those needed for supporting healthy women and families. In this couching of a bioethicist's role, social analysis plays a key part. However, not all current approaches to bioethics and infant mortality are attentive to social analysis. There are different traditions of bioethical thinking about ethical principles, and some are better geared than others toward recognizing the power dynamics at play at the intersection of race, class, and gender inherent to the situation of infant mortality. Therefore I would add that the bioethicist's role is also to recognize that there are a variety of "methods in a system of abstract knowledge," they are all historically and culturally embedded, some are more fitting to certain problems than others, they can be complementary, and it is part of the bioethicist's role to assess which methods can best respond to the problem at hand.

I find that this understanding of how the work of bioethicists can make a difference in infant mortality resonates with a particular conceptualization of the field of bioethics itself. Specifically, feminist and sociological descriptions are particularly apt for encompassing the depth and breadth of a bioethical approach that can adequately assess the complex factors relating to infant mortality. For Petya Fitzpatrick and Jackie Leach Scully, who claim feminist bioethics as a social location for their work and research, "bioethics is both practical and theoretical, responding to ethical problems arising from the practice of modern medicine."<sup>7</sup> This description is helpful both in breadth and scope—bioethics is *both* theory and practice, and the field of study of bioethics is concerned with any and all ethical issues arising in health care.

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<sup>7</sup>Put more simply by feminist bioethicist M.C. Rawlinson, bioethics is "an ethics founded in and reflective of life." Petya Fitzpatrick and Jackie Leach Scully, "Introduction to Feminist Bioethics," in *Feminist Bioethics*, eds. Jackie Leach Scully, Laurel E. Baldwin-Ragaven, and Petya Fitzpatrick (Baltimore: The Johns Hopkins University Press, 2010), 1.

Within this framing, we can imagine a bioethics that is attentive to the life stories of individuals, and that is done in the academy and in the community; in the classroom and in the clinic.

Rose Weitz's sociological perspective adds important considerations for a bioethics that is attentive to social vulnerabilities: "Bioethics is the study of ethical issues in biological sciences and health care. Many of the issues bioethicists ponder revolve, whether explicitly or not, around the use and impact of power."<sup>8</sup> Indeed, the issue of infant mortality, where intersections of race, class, and gender compound hierarchical relationships with health care systems and government agencies, must be able to grapple with uneven power dynamics.

Thus, this particular understanding of bioethics I am advocating for differs from more commonplace definitions of the field often found in working practice among medical professionals. Indeed, many perceive bioethics to focus on ethical deliberation about medicine in response to the rise of technological advancements in the mid-twentieth century. For example, Bernard Lo, well-known physician and author of *Resolving Ethical Dilemmas: A Guide for Clinicians*, now in its fifth edition, distinguishes bioethics from clinical ethics because it "refers to broader philosophical questions raised by biomedical advances, for example, whether genetically modified crops or germ-line gene therapy is acceptable."<sup>9</sup> Lo's perspective, undoubtedly common among health care practitioners and the public, unnecessarily assumes that the kinds of work bioethicists can contribute relates primarily to questions of new research and new technologies or therapies. Unfortunately, his assumption of the scope of bioethics too easily

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<sup>8</sup>Rose Weitz, *The Sociology of Health, Illness, and Health Care: A Critical Approach*, 6<sup>th</sup> ed. (Boston: Wadsworth, 2013), 334.

<sup>9</sup>Bernard Lo, *Resolving Ethical Dilemmas: A Guide for Clinicians*, 5<sup>th</sup> ed. (Philadelphia: Lippincott Williams & Wilkins, 2013), 4.

separates ethical questions about technology from their implications in health care, public policy, research, and culture.

While I agree bioethicists ought to be concerned with advances in technology, the field is much broader than the range of these topics. There is a vast disconnect between bioethics in practice in health care systems and public health policy, that carry on this narrowed view of bioethics, and more recent trends in feminist and sociological bioethics.<sup>10</sup> These descriptions provide a much needed reframing of what bioethicists should concern ourselves with if we are to accurately portray and contribute to complex moral questions like infant mortality.

Let us now turn our attention to the methods used by bioethicists. If we follow Evans and agree that bioethicists use methods in a system of abstract knowledge to articulate the values of a community and base recommendations upon them, which methods are these? In particular, which methods ought to be used by a bioethicist working on infant mortality? To be sure, there are many modes of ethical reasoning that have come to different degrees of prominence in bioethical thinking: casuistry, narrative ethics, feminist ethics, ethics of care, liberationist ethics, approaches grounded in human dignity and vulnerability, and others. However, one method in particular has risen to prominence in all areas of contemporary US bioethical reasoning and activity.

### **Principlism and a Critique of Pragmatism**

In 1976, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was given a congressional mandate to “identify the ethical principles

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<sup>10</sup>These are not the only vantage points for bioethics that have also incorporated understanding of the intersections of race, class and gender: narrative bioethics and critical bioethics are two such approaches that are also attentive to these realities.



which should underline the conduct of biomedical and behavioral research with human subjects and develop guidelines that should be followed in such research.”<sup>11</sup> They looked to existing codes of ethics as well as several essays on moral principles and their application to research. The commissioners initially identified seven principles to guide ethical human subject research practices. After discussion, this list was pared down to three: respect for persons, beneficence, and justice.

It is understandable how the National Commission came to settle on these three ethical principles. As physician Robert J. Levine points out, “the National Commission was charged to identify, not to invent, the basic ethical principles,” and therefore relied in part on published treatises, including the Nuremberg Code, as a basis for their deliberation.<sup>12</sup> The 1946 judgement in “The Doctor’s Trial”—where seven Nazi doctors were sentenced to death for conducting human experiments that were declared war crimes and crimes against humanity—produced the Nuremberg Code, which delineates core commitments for human experimentation ethics. In the views of scholars George J. Annas and Michael A. Grodin, the Nuremberg trials made it apparent that “the need to respect the humanity and self-determination of all humans is central to the ethos not only of medicine and human experimentation but of all civilized societies.”<sup>13</sup> Components of respect for persons, beneficence, and justice are integrally woven into this code.

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<sup>11</sup>Albert R. Jonsen, “On the Origins and Future of the *Belmont Report*,” in *Belmont Revisited: Ethical Principles for Research with Human Subjects* ed. James F. Childress, Eric M. Meslin, and Harold T. Shapiro (Washington, DC: Georgetown University Press, 2005), 3.

<sup>12</sup>Robert J. Levine, “The National Commission’s Ethical Principles, With Special Attention to Beneficence,” in *Belmont Revisited*, 9.

<sup>13</sup>George J. Annas and Michael A Grodin, “Introduction,” in *The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation* eds. George J. Annas and Michael A Grodin (Oxford: Oxford University Press, 1992), 4, 7.

As Dr. Jay Katz saw it—whose 1972 text *Experimentation with Human Beings* was on the reading list for the Belmont commissioners—the voluntary consent of the human subject “constitutes the significance of the Nuremberg Code then and now.”<sup>14</sup>

Closer to home, the commissioners were also responding to disturbing medical research practices in the United States. A prime example includes the 600 Black men in Macon County, Alabama, who were the subjects of a study of the effects of untreated syphilis. In 1972, public attention was called to the fact that for forty years, the Public Health Service (PHS) tracked the medical condition of 399 Black men with late stage syphilis, as well as 201 Black men in a control group, in exchange for free physical examinations, free rides to and from the clinics, hot meals on examination days, free treatment for minor ailments, and free burial insurance.<sup>15</sup> While it is not true that study subjects were injected with syphilis, there were ethically problematic elements of the PHS study of syphilis at Tuskegee. These included that the men in this study were not told of the study’s purpose; those with syphilis were not informed that they had this diagnosis or what their prognosis may be; and, most egregious, when a safe and effective treatment for syphilis was identified in the 1940s, the men with syphilis were deliberately kept from treatment.<sup>16</sup> As Commissioner Albert R. Jonsen put it, the PHS study at Tuskegee was “the shameful reminder” of the “common, but invidious practice of burdening the indigent sick with

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<sup>14</sup>“The Birth of the Belmont Report,” <https://bioethicsarchive.georgetown.edu/nbac/transcripts/jul98/belmont.html> (accessed January 20, 2017).

<sup>15</sup>James H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment* (New York: The Free Press, 1993), 1, 4.

<sup>16</sup>*Ibid.*, 1, 5-6, 8.

research.”<sup>17</sup> This concern for ethical selection of research subjects became the underpinnings for the inclusion of justice as a *Belmont* principle.

The commissioners were guided, then, first by The Nuremberg Code, interpreted as a champion of respect for persons through voluntary consent. Also, their work was informed by the 1972 whistle-blowing by a journalist of the PHS study at Tuskegee, a reminder of the importance of fair and just distribution of the burdens of research. And, as Jonsen also remarked,

Beneficence and its correlate, nonmalefeasance, was an obvious addition, since all previous statements on the ethics of research from Claude Bernard to Pope Pius the 12th, from Nuremberg and Helsinki, admonished the researcher not to harm the subject.<sup>18</sup>

Not to mention Hippocrates. From this view of history, it is understandable indeed that the commissioners landed upon specific ethical principles of respect for persons, beneficence, and justice, as well as the ways in which these principles were described and understood.

However, as will be discussed below, there are other histories unfolding at the same time that, if paid close attention to, may have prompted different discussions about ethical principles for medical research.

Just months after the commissioners first met and identified these three principles, Tom L. Beauchamp joined the staff of the National Commission and was tasked with writing what became *The Belmont Report*. Beauchamp and his colleague James Childress, both trained in theology and Christian ethics as well as philosophy, were concurrently working on *Principles of Biomedical Ethics*. The two texts inevitably influenced one another.<sup>19</sup> While *Belmont*'s scope

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<sup>17</sup>“The Birth of the Belmont Report.”

<sup>18</sup>Ibid. “Nonmalefeasance” is the spelling from the transcript.

<sup>19</sup>Tom L. Beauchamp and James F Childress, *Principles of Biomedical Ethics*, 6<sup>th</sup> ed. (Oxford: Oxford University Press, 2009), 15.

was limited to human subject's research, *Principles of Biomedical Ethics* more widely addressed the field of bioethics. *Principles of Biomedical Ethics*, today in its sixth edition, puts forth four ethical principles: respect for autonomy (instead of respect for persons), beneficence, nonmaleficence (now separated from its counterpart), and justice. These four mid-level principles, said to represent the values of the common morality, are to be balanced in a particular way in order to arrive at an ethically appropriate decision that can be agreed upon by all parties.<sup>20</sup> Sit in on any introductory course to bioethics or grand rounds lecture on ethical issues in modern medicine and you will be sure to hear reference to these principles. "The principles approach" is noted by Evans to be "by far the most influential method of the bioethicists" still today.<sup>21</sup>

As Evans notes, "Principlism is here to stay."<sup>22</sup> Beauchamp and Childress succeeded in presenting a principles-based approach to ethical decision making that appealed to a wide net of scholars and practitioners working in different disciplines. For example, in the sphere of health care ethics consultation, many professionals practice bioethics part-time in addition to their responsibilities as physician, nurse, social worker, or chaplain. An easily accessible set of principles within a straightforward framework appealed to this variety of professionals whose time was split between these dual roles. In their attempt to provide a common language for ethics speak among people with diverse values and beliefs, Beauchamp and Childress shied away from the religious language of their training and opted for terms that they believed to be more neutral and accessible in a pluralistic society.

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<sup>20</sup>Ibid., 23.

<sup>21</sup>Evans, *The History and Future of Bioethics*, 45.

<sup>22</sup>Ibid., 140.

The aim of accessibility resulted in some shortcomings. As Christian medical ethicist Allen Verhey points out:

when, for the sake of pluralism, we require a secular and religiously neutral moral language, some moral “Esperanto,” then we require people to deny that they belong to particular communities—at least in public. The irony of universal languages like Esperanto, of course, is that hardly anyone speaks them.<sup>23</sup>

When particular communities give up their specific language for the sake of embracing and negotiating pluralism, inevitably deep understanding of distinctive theological images and metaphors that can enliven moral language will be lost. While it may be true that these abstract principles allowed those from different disciplines doing work in bioethics to talk to each other, adopting them came at the risk of losing some moral sentiment in translation. Additionally, a common language for bioethics does not always translate well to stakeholders outside the bioethics realm who may have found meaning in moral or religious language, whether it was the language of their own community or another with which they were familiar.

Other concerns include that the principles espoused by this method are so formalized and abstract that in practice, they are not informed by values of particular communities and people. As Evans points out, while Beauchamp and Childress claim to present principles that represent the common morality of the public, “their method of empirically determining the values or principles of the public suggests a reluctance to allow the public’s values to drive bioethical conclusions.”<sup>24</sup> A related flaw is the

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<sup>23</sup>Allen Verhey, *Reading the Bible in the Strange World of Medicine* (Grand Rapids: Eerdmans, 2003), 22.

<sup>24</sup>*Ibid.*, 127.

assumption that all agree on what respect for autonomy means, and what justice entails.

For example, when a pragmatic approach to respect for autonomy focuses on a check-box approach to informed consent, it may not be robust enough to consider potential social and cultural constraints on moral agency. If the framework used by bioethics indeed fails to represent the social realities faced by the public, perhaps there is merit to paying better attention to the actual moral values, traditions, and beliefs of its constituent groups.

Indeed, the pragmatic turn in some popular applications of the principles approach is also concerning. Evans shows that the increase of governmental jurisdiction over the spheres of activity where bioethicists work has led to a preference for principlism's logical system of prediction and calculation.<sup>25</sup> Principlism is appealing to institutions steeped in hierarchy and bureaucracy because it makes bioethical decision-making more formulaic. Evans even contends that "the principles were created to enhance calculability or, in more common language, to simplify bioethical decision-making." To make this point, Evans cites a text Beauchamp penned in 1995: Beauchamp wrote that the principles "provide frameworks of general guidelines that condensed morality to its central elements and gave people from diverse fields an easily grasped set of moral standards."<sup>26</sup> By prioritizing accessibility in a pluralistic society, Beauchamp and Childress sacrificed not only religious language, but also its relevance to bioethical questions. This quelling of religious language in bioethics has especially unfortunate effects for bioethical questions wherein a Western philosophical framework is not sufficient, or where social analysis

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<sup>25</sup>Ibid., 48-52. Evans calls this system "commensuration."

<sup>26</sup>Ibid., 52. Citing Tom Beauchamp, "Principlism and Its Alleged Competitors," *Kennedy Institute of Ethics Journal* 5, no. 3 (1995): 181-198.

is needed. This condensing of morality also affects which bioethical issues are raised to the level of public outcry and response, and which are left festering and untended.

While admittedly helpful for those part-time practitioners, the thought of practicing a condensed version of morality may make these and others feel uneasy. It is unsettling to reflect on the fact that the way bioethics is practiced in health care systems and offices of public health may not be robust enough to adequately consider the full situations and needs of persons—whether as research participants, patients, or members of the public—in their most vulnerable moments.<sup>27</sup> Perhaps some cases of bioethical deliberation should not be simplified, and should take additional principles and frameworks into account. However, the popularity of principlism diminishes the place of other ethical methods, norms, traditions and principles that are important for bioethical work. Two such examples include feminist ethics of care and narrative ethics, which, while offering different approaches to bioethics, are often seen as secondary to principlism.

Indeed, despite its widespread use, there are many critiques leveled against this form of principlism. Though Beauchamp and Childress develop a wider application of these principles than the realm of research, health care professionals may well find it off-putting that principles intended as a baseline for human subjects research came to serve as the foundation for all

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<sup>27</sup>Even well-intentioned attempts to pay attention to vulnerability can have adverse effects when a principles-based approach is applied. Take for example guidelines surrounding human subject's research for pregnant women. Under the Common Rule, pregnant women have been considered vulnerable subjects deserving of protections in research. This rule states that "pregnant women or fetuses may be involved in research," as long as certain conditions are met. Recent scholarship has pointed out that in practice, these regulations set up a barrier to including pregnant women and fetuses in research. As they point out, "The main problem with the Common Rule is that it is phrased in such a way that including pregnant women in research is optional." Chris Kaposy and Francoise Baylis, "The Common Rule, Pregnant Women, and Research: No Need to "Rescue" That Which Should Be Revised," *American Journal of Bioethics* 11, no. 5 (2011): 60.62.

bioethical reasoning. It can readily be argued that what is owed to research subjects is different from what is owed to patients, and that each of these will be distinct from that which is owed to the general public. Recognizing the difference in relationships between patient and physician, principal investigator and research subject, and public health official and citizen ought to make us take a second look at whether ethical principles designed for human subject research are one-size-fits-all when considering health care and public policy. While *The Belmont Report* identified just three principles, it states that “other principles may also be relevant.”<sup>28</sup> The commissioners may well have agreed that when it comes to the realms of health care and public policy, there may be different ethical principles more relevant to these areas. The *de facto* acknowledgement of Beauchamp and Childress’s principles as the starting point for all bioethical deliberation, then, is open to challenge.

There are many reasons that scholars find the widespread use of this particular form of principlism to be problematic. As discussed by Black Catholic bioethicist Shawnee Daniels-Sykes, these principles are derived from Eurocentric philosophical theory that tends to ignore racial and socioeconomic vulnerabilities that play a key role in abuses of medicine.<sup>29</sup> Beauchamp and Childress appeal to major philosophers such as Aristotle, Immanuel Kant, and Jeremy Bentham to derive their principles, then purport to ground a “common morality” from these Western traditions of moral reasoning that are keen to theorize. Daniels-Sykes holds that “the

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<sup>28</sup>National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont Report*, April 18, 1979, accessed January 15, 2017 <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html>

<sup>29</sup>Shawnee Daniels-Sykes, “Code Black: A Black Catholic Liberation Bioethics,” *The Journal of the Black Catholic Theological Symposium* 3 (2009): 44-46.



commissioners charged with the development of *The Belmont Report* failed to protect *all* human subjects in a holistic manner,” citing the inadequacy of these principles for addressing the situation of racially and economically vulnerable populations.<sup>30</sup> In the minds of Daniels-Sykes and others, the ethical significance of the PHS Study at Tuskegee is profound because it spotlights the continuation of a legacy of medical abuses against persons of color in the modern age of research oversight. Jonsen’s more generic reminder of the importance of justice in choosing research subjects, while important, misses this point. Simply put, Daniels-Sykes and others rightly point to the need for social analysis in bioethics.

Belmont Commissioner and Christian feminist ethicist Karen Lebacqz shows how the shift in language from *Belmont*’s “respect for persons” to “respect for autonomy” is another area of concern. Lebacqz led the National Commission subgroup that initially identified seven ethical principles. She points out that while “in the National Commission’s view, *all* people, *all* human beings, are deserving of respect... the shift in language [from respect for persons to respect for autonomy] suggests that nonautonomous persons are not deserving of respect.”<sup>31</sup> Lebacqz’s critique is on point for our concern with infants, a group who are unquestionably nonautonomous. It is also helpful for considering what is owed to fully autonomous persons whose moral choices are constrained by socioeconomic conditions.

Lebacqz continues her critique, stating “the truncating of respect for persons into respect for autonomy” results in “the exclusive focus on *autonomy* in defining persons.”<sup>32</sup> She rightly

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<sup>30</sup>Ibid., 45.

<sup>31</sup>Karen Lebacqz, “We Sure Are Older But Are We Wiser?” in *Belmont Revisited*, 101.

<sup>32</sup>Ibid., 100.

acknowledges that not all agree on this anthropological view, pointing out that “feminist literature has stressed not autonomy and its implications of choice and freedom, but *relationality* and its implications of connection and commitment.”<sup>33</sup> She then reveals how in our individualistic culture, autonomy has further shifted its meaning, from a Kantian understanding of the categorical imperative to unfettered freedom of choice.<sup>34</sup> Perhaps Katz’s reduction of the significance of Nuremberg to voluntary consent achingly overlooks incredibly important lessons from the Holocaust about what it means to be human and treated as such. These are lessons that should be paid attention to by bioethicists.

We can revisit the Holocaust and the PHS Study with a fresh lens to see how a view attentive to social vulnerabilities and informed by power differentials in race, class, and gender makes a difference in the kinds of methods and principles put to use by bioethicists. A more intersectional view of history challenges us to see that respect for persons, means much more than freedom of choice. It is estimated that 350,000 to 400,000 men and women in Germany were forcibly sterilized after being found to suffer from “genetically determined” illnesses under the auspices of “racial hygiene” or eugenics.<sup>35</sup> While it is indeed an affront to the dignity of each person who experienced sterilization against their will, focusing on the Nazi regime’s failure to provide informed consent or respect a person’s refusal seems to miss the point. A common

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<sup>33</sup>Ibid.

<sup>34</sup>Onora O’Neill, *Autonomy and Trust in Bioethics* (Cambridge: Cambridge University Press, 2002).

<sup>35</sup>Robert N. Proctor, “Nazi Doctors, Racial Medicine, and Human Experimentation,” in *Nazi Doctors and the Nuremberg Code*, 20-21. Targeted sterilizations of women of color without informed consent has taken place in the United States as well. See Harriet A. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (New York: Doubleday, 2006). Dorothy Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York: Vintage Books, 1997).

commitment to affirming the dignity in the diversity of humanity and protecting those most vulnerable in society, regardless of genetic makeup or self-determination, better represents the moral worldview put at stake by Nazi sterilization practices.

Similarly, a view of history attentive to social vulnerabilities presents a more complex duty of justice. In Alabama, 89 wives of men who were in the PHS Study at Tuskegee tested positive on serologies for syphilis. Medical records reveal that miscarriages and deaths of children abounded, wherein it is unknown whether syphilis may have played a role.<sup>36</sup> Deeming the significance of the PHS Study at Tuskegee as an unfairly distributed burden of research upon a particular group of poor Black men in Macon County, while true, is not a broad enough lens of justice to fully encompass the detriment of this study to the lives of these men, their families, and their communities. Without listening to the accounts of women affected by the PHS Study at Tuskegee—and likewise, the Black mothers in Milwaukee who are most affected by infant mortality—how are we to ensure that the scope of justice is adequate? Perhaps we would do better to follow Lebacqz and, instead of beginning with a theory of justice, start with identifying injustices like these and recognizing common threads to begin to see how we can better attend to injustices.<sup>37</sup>

If we take as our starting point the recognition of abuses in medicine and insufficient public health policies as unjust affronts to human dignity, we can begin to practice a kind of bioethics that is attentive to social vulnerability. To be sure, certain thinkers and movements in

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<sup>36</sup>Susan M. Reverby, *Examining Tuskegee: The Infamous Syphilis Study and Its Legacy* (Chapel Hill: The University of North Carolina Press, 2009), 130. While some of these may have been false positives, Reverby notes this is still a sobering figure.

<sup>37</sup>Lebacqz, *Justice in an Unjust World*, 7.

modern bioethics have widened their focus to consider the large role social determinants of health play in our lives. Bioethicists do not need to completely eschew the principles of respect for persons, beneficence, and justice to be attentive to social vulnerabilities; indeed, these concepts can still play helpful roles within a robust ethical analysis. However, when applied within a narrow framework that simplifies bioethical deliberation to weighing of abstract principles, ethical analysis can be reduced to mere academic exercise, perhaps recommending short-term fail safes and ideal future states, but ultimately failing to holistically respond to real need. To illustrate these kinds of limits inherent in the principles approach, consider the following case study.

### **Prematurity Case Study: An Illustration of the Limits of Pragmatic Principlism**

Case study discussion is a common way for medical residents to learn. Often during morning rounds, a group meeting where each patient's care plan is discussed, the attending resident physicians for a particularly complex patient will present their patient's case. Some background to the case is given, other residents around the table ask clarifying questions and for test results relating to different organ systems, and then as a team they collaborate on a differential diagnosis. Or, they may discuss an interesting or complex case in retrospect, or a case study from a journal article. At times, discussions of ethical issues in patient care can become the focus of these case conferences. Imagine a group of residents who practice obstetrics and their supervising faculty discussing this case, taken from a 1994 case-based text for OB/GYN residents, of a premature infant:

An 18-year-old, gravida 1, para 0, single patient with an intrauterine gestation of 24 weeks by dates and 23 weeks by ultrasound had rupture of membranes one-half hour prior to admission. She was transferred to the labor and delivery area, where rupture of membranes was confirmed. Her temperature was 38.4 °C, and her uterus was markedly

tender with contractions. The fetal heart rate was 180 beats per minute with no variability and severe late decelerations. She discusses potential fetal risks at delivery and states that she does not want cesarean delivery unless it is to save her life, nor does she want resuscitation done since the chance of fetal survival seems low. A neonatology fellow comes in to discuss this decision with her and claims that “All live born babies must be resuscitated here. You have no right to not give this baby a chance!” She becomes distraught, and the resident is called to “settle the issue.”<sup>38</sup>

First, there are a few anachronisms here that need to be addressed. The commentary following this case study states, “Clinical experience would indicate that even if able to be resuscitated, this infant’s chance for survival is virtually nonexistent.”<sup>39</sup> To the authors, this certitude is most likely based on the estimated gestational age of 23-24 weeks. Since the time of this case study’s publication, subsequent research has shown that the estimation of gestational age by a variety of methods is not reliably accurate to within one week. Also, gestational age is not the only factor helpful in predicting outcomes for extremely preterm infants; fetal weight is also an important indicator, and these estimates can be inaccurate by as much as 15-20%. While the number of prematurely born infants who survive has increased, there is still uncertainty in prognosticating outcomes for individual babies.<sup>40</sup> Despite these uncertainties, in 2002 The American Academy of Pediatrics wrote that it is appropriate to not initiate resuscitation at 23 weeks gestation; no updated recommendations have been published since.<sup>41</sup> Therefore, the

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<sup>38</sup>Association of Professors of Gynecology and Obstetrics Task Force on Medical Ethics, *Exploring Medical-Legal Issues in Obstetrics and Gynecology* (Washington, DC: Association of Professors of Gynecology and Obstetrics, 1994), 60. Case study taken verbatim.

<sup>39</sup>*Ibid.*, 61.

<sup>40</sup>Julie R. Swaney, Nancy English, and Brian S. Carter, “Ethics, Values, and Palliative Care in Neonatal Intensive Care,” in eds. Sandra L. Gardner et al., *Merenstein and Gardner’s Handbook of Neonatal Intensive Care* (St. Louis: Elsevier, 2016), 930.

<sup>41</sup>American Academy of Pediatrics, Committee on Fetus and Newborn, “Perinatal Care at the Threshold of Viability,” *Pediatrics* 220 (2002): 1024-1027.

residents would likely discuss that an estimated gestational age of 23-24 weeks in this day and age does not give us certainty about the likelihood of survival when this infant is born.

Given this information, which complicates the situation above even further, what might a principles-based approach to ethical analysis of this case look like? Perhaps a faculty member at the table asks one of the presenting residents to identify ethical principles that are relevant. Inevitably, respect for autonomy would be named, and the role of the patient in making her own medical decisions and discerning the best interest of the child would be discussed.<sup>42</sup> Indeed, the residents may bring up differences in the American interpretation of the role of parents in determining the best interest of the child versus other countries. This concern may be due to the highly publicized case of Charlie Gard, an infant in London whose course of medical care included legal involvement in evaluating the appropriateness of experimental treatment to a degree we do not see in the United States.<sup>43</sup> The importance of informed consent would be highlighted. Let's imagine that the residents conclude that the patient ought to be provided sufficient information to make decisions she believes to be in the best interest of herself and her infant, and turn to a discussion of beneficence and non-maleficence to assess risks and benefits.

Seeking the good of both the mother and her unborn child, while also avoiding unnecessary harm to them, would then couch a conversation about how to present various options to the patient. The risk-benefit calculus of preterm labor management strategies and caesarian delivery would be considered based on the patient's health history and current clinical

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<sup>42</sup>Discussions among the residents about personhood, human dignity, and respect for life in relation to the unborn fetus may also arise. However, if residents are focused on the four principles of respect for autonomy, beneficence, nonmaleficence, and justice, this discussion may be overlooked.

<sup>43</sup>BBC News, "Charlie Gard: The Story of His Parents' Legal Fight," <http://www.bbc.com/news/health-40554462> (accessed January 10, 2017).

situation. The risks and benefits of infant resuscitation would also be discussed in light of factors like the estimated gestational weight, estimated gestational age, and the infant's APGAR score and appearance at birth. The residents may discuss using these calculations to determine what options are most clinically sound to present to the patient, thus fulfilling the duty to provide information about the benefits and burdens of treatment options in order to enable an informed consent process. They may also look at whether palliative care may be beneficial in this situation, or as an acceptable alternative treatment, and provide the patient this information as well.

Having considered three of the four Beauchamp and Childress principles, someone around the table would inevitably ask "What about justice?" In my experience, justice often becomes the most intangible concept of the four for medical residents to apply in this type of case study review. At times, a discussion of allocation of medical resources ensues. In this case, a resident or faculty member may wonder aloud whether we ought to justify costly NICU care for an infant who is unlikely to survive. The counterargument of the uncertainty of survival predictions for any particular extremely premature infant would then come up: since we don't know who will survive, we ought to give all the chance. Whether larger questions of social justice come into this conversation is not guaranteed. When they do, as exemplified by Yale emeritus professor of pediatrics and neurology Geoffrey Miller's poignant ethical analysis of extremely premature infants, biases skewed toward inaccurately predicting survival and failing to recognize the inherent dignity of these most vulnerable persons are uncovered.<sup>44</sup> In addition,

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<sup>44</sup>Geoffrey Miller, "Extreme Prematurity: Truth and Justice," in ed. Geoffrey Miller, *Pediatric Bioethics* (Cambridge: Cambridge University Press, 2010), 145-146.

implicit biases influenced by a capitalistic emphasis on economic status as representative of worthiness of medical resources can also play a part. While bringing up important considerations of justice to be sure, Miller's analysis of justice in treating extremely premature infants is limited to the NICU environment, and does not evaluate the social conditions that may have contributed to the child being born prematurely in the first place.

After the fourth principle is discussed, the group would attempt to weigh all considered options against one another. Respect for autonomy, distilled down to freedom of choice, may seem to rule. While this may be seen as the end of the ethical analysis via the principles method, with a group of compassionate and caring residents, this will not be the end of the discussion. They would talk about the lone social identifier in the case study description, that the patient is "single," and wonder about other components of her identity. What is her social location? Who is her support system? Who helps her make tough decisions? Can we call them, so they can accompany her? Would she appreciate a chaplain referral? While contemplating these questions may be seen as "caring," or "interesting," and an important part of the case conference, they would likely not be considered to be at the heart of the ethical problem. While these questions may be seen as irrelevant for clarifying how the four mid-level principles are at play, they are exactly the kinds of questions that are important for linking ethical analysis of individual cases of prematurity and infant death to ethical practices that can prevent them in the first place.

The inadequacies of principlism for attending to the intersectional social vulnerabilities at play when considering bioethical responses to infant mortality are clear. A focus on autonomy, reduced to freedom of choice, as that which needs to be protected does not adequately account for children or represent relationality and vulnerability as central components of personhood.



The reduction of beneficence and non-maleficence to a risk-benefits calculus focused on the research method or medical intervention at hand fails to provide the fluidity to consider how the particularities of individual lives shape moral decision making. And, a superficial concept of justice, understood as ensuring fairness in the distribution of burdens and resources, is nebulous when considering how historical and social factors shape moral action.

Thankfully, there are other methodologies besides principlism that not only pay heed to social determinants of health, but put them at the center. An ethical methodology that seriously considers social vulnerabilities gives room for reshaping principles related to justice and respect for persons that can evaluate potential unjust relationships that lead to the onset of premature labor in the first place. In Milwaukee, where we know babies with darker skin die three times more often than White babies, a method of ethical deliberation that pays attention to race, class, and gender may raise significant recommendations and implications for public policy, research, and culture. While not the only discipline that can offer a different starting point and way of doing bioethics, Christian bioethics, for its part, is concerned for the most vulnerable, and contains resources for addressing systemic social ethics questions that are left unanswered in mainstream bioethics.

### **Central Commitments for the Reshaping of US Bioethics**

As discussed at the beginning of this chapter, scholars from many fields engage in the work of bioethics. It is my perspective that Christian bioethics can offer important ways of thinking about and responding to the ethical questions raised by the current situation of infant mortality. Catholic theologian Lisa Sowle Cahill posits that theological language can do much to

elevate the profile of justice in public discourse, and that religious narratives and symbols can help widen the moral imaginations of those from diverse traditions and faiths. She also offers:

Theological bioethics is not just about talk. It is about action. The “truth” and viability of the vision of Christian theological bioethics is warranted not just by cogent theory or argument but by the emergence of transformative practices that join with other movements in global civil society to encourage human solidarity, empower “the poor,” and motivate the powerful to change.<sup>45</sup>

Here, Cahill calls for a bioethics that can move from cogent theory and argument to transformative practices and action, and that is grounded in shared commitments that inspire and motivate change. Christian bioethics, for its part, presents religiously-grounded concepts, language, narratives, and symbols that I believe can effectively respond to the complexities of infant mortality.

To understand how this kind of bioethical enterprise is distinctively Christian, it is helpful to consider Cahill’s framing of theology and theological ethics. She contends:

“Theology” is essentially a process of reflection on religious experience in which the systematic coherence of religious narratives and symbol is clarified and their practical ramifications are developed. Theological ethics is the explication and defense of the personal moral and the social behavior required or idealized by a religious tradition.<sup>46</sup>

Reflecting on biblical texts, traditional practices, and Christian symbols can lend moral insight to those moral values that are important for Christians. While Christians are by no means a monolithic group, they do share these sources of moral wisdom in common. Also note Cahill’s inclusion of developing *practical ramifications* as a defining part of the work of theology. With

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<sup>45</sup>Lisa Sowle Cahill, *Theological Bioethics: Participation, Justice, Change* (Washington DC: Georgetown University Press, 2005), 2.

<sup>46</sup>*Ibid.*, 15.

this focus we can begin to see how Christian ethicists have unique expertise in evaluating value-laden social questions with diverse partners and posing courses of moral action.

Cahill affirms that theologians are particularly adept at responding to moral questions in bioethics. She notes the prevalence of theologians involved in bioethical discourse in the mid-twentieth century, and reminds us that religious communities have “cultivated long-standing traditions of reflection on life, death, and suffering.”<sup>47</sup> These areas of inquiry mirror back many of the same ethical questions faced in studying infant mortality. While acknowledging that theologians may not be as active in spheres of bioethics as they once were, Cahill simultaneously wishes to reignite their participation:

the challenge to theology is to recover its religiously distinctive prophetic voice and enter into policy debates as an energetic adversary of the liberal consensus. Theologians ought to stick to their own convictions, remain unapologetically theological in orientation, while still seeking common cause and building a common language with all who are similarly committed to health care justice.<sup>48</sup>

Cahill contends that theologians can stay true to their Christian commitments without having to build consensus about principles for a common morality, while at the same time working together with others to seek justice. Indeed, Cahill maintains that “religious narratives and symbols can also have a public role in widening the moral imaginations of people from diverse traditions and faiths.”<sup>49</sup> Verhey echoes this sentiment: “the accumulated wisdom of particular religious traditions and communities frequently illuminates not just the meaning of a particular

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<sup>47</sup>Ibid.

<sup>48</sup>Ibid., 18.

<sup>49</sup>Ibid., 2.

religious identity but also and often the meaning of our common humanity.”<sup>50</sup> There is good reason to believe that the public is interested in moral values rooted in religion, because the public is made up of both religious persons and groups of people who seek to understand those different from themselves and live peaceably with them.

How can a Christian bioethical framework lead to moral analysis and practices that will appeal to diverse partners within a pluralistic community? To be sure, some groups of Christians, especially those who solder their religious beliefs to essential political beliefs may already be seen by many to have too much say in American society.<sup>51</sup> While religious appeals have the potential to divide, I believe in the case of responding to infant mortality in Milwaukee the potential to unite is greater. Christians and non-Christians can come to appreciate the contributions Christian ethical traditions can make to responding to infant mortality. As an example, the four of my collaborators who are health care professionals remarked to me that faith is an important support for some of their patients, and that they see churches as having a vital role in supporting women, infants, and families who are under-resourced in our community.

Consider how a particular theological understanding of vocation that is part of the Christian tradition can be brought into conversation with community partners of diverse religious and cultural beliefs to inspire common action. “Vocation,” broadly defined as one’s sense of purpose, is a concept that is intelligible to both religious and secular persons. From this common ground, a Christian lens can enrich the concept further. For example, Catholic systematic and

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<sup>50</sup>Verhey, *Reading the Bible*, 22.

<sup>51</sup>For example, those who equate their practice of Christianity to their stance on White nationalism/supremacy, reproductive rights, or end of life care.

Womanist theologian M. Shawn Copeland reflects on the specific calling of a theologian. In doing so, she provides a powerful description of the theologian's vocation:

We do theology because we want to collaborate fundamentally in bringing about a different kind of world in the here-and-now. Our contribution to the project is to think about the world in light of the eschatological future that only God can give. We advocate for the reign of God.<sup>52</sup>

One way to translate this reflection on a Christian theologian's vocation is to say that we haven't really done theology if we haven't considered how whatever we are doing affects the lives of real people. A key part of bringing about social change is collaboration, undoubtedly with Buddhist, Muslim, Jewish, Hindu, and secular humanist partners who each draw on specific norms and understandings rooted in their traditions to share with and encourage one another in thinking about how to bring about justice. Sharing complementary visions of justice can help interreligious and secular partners all think more openly and creatively to reimagine how to ameliorate injustices in the daily lives of those bearing unfair burdens in our society. Work done together to build a consensus around what we are called to do in the name of justice, albeit lengthy and prone to veer off track from time to time, can be enriched by stories and images from multiple traditions along the way. As Dr. Martin Luther King, Jr. reminds us, "the arc of the moral universe is long, but it bends toward justice."<sup>53</sup>

To bring Copeland's vision to bear on the topic of infant mortality, we might consider how the calling to be a nurse or physician contains the complementary visions of bringing about justice in the lives of patients. Health care professionals of different backgrounds who see their

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<sup>52</sup>M. Shawn Copeland, "Racism and the Vocation of the Theologian," *Spiritus* 2 (2002): 26.

<sup>53</sup>Rev. Dr. Martin Luther King, Jr., "Sermon at Temple Israel of Hollywood," February 25, 1965.

work as a calling may appreciate coming to know a Christian perspective on what the reign of God would look like in the here-and-now. The prophetic voice of Isaiah offers this vision:

I will rejoice in Jerusalem, and delight in my people; no more shall the sound of weeping be heard in it, or the cry of distress. No more shall there be in it an infant that lives but a few days, or an old person who does not live out a lifetime; for one who dies at a hundred years will be considered a youth, and one who falls short of a hundred will be considered accursed. (Isaiah 56:19-20)

We can envision that the society intended for our world is this City of God, and that this future entails the end of the unjust deaths of infants. No longer will their mothers and fathers, sisters and brothers, neighbors and friends, nurses and doctors weep or cry out in distress. This is a vision that may well appeal to many different constituencies, whether they have religious or secular commitments, or professional or personal callings, that motivate them to engage in action for social justice.

This passage, while from the Hebrew Bible and thus rooted in both Jewish and Christian traditions, offers up an evocative vision that might encourage broad groups of people to muster the purpose and drive needed to combat premature infant death. Concern for infants and children, considered as vulnerable members of society, is a common thread that runs through many cultures, religions, and contexts. For example, a secular translation of this vision is often stated as a simplified purpose statement for the Strong Baby Sanctuary Program: “helping more babies celebrate their first birthdays.”<sup>54</sup> While this particular vision from Isaiah may be the direction in which Christian bioethicists set their compass, I welcome that other partners may use other moral narratives or symbols that are meaningful for them. The hope is that moral commitments from

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<sup>54</sup>I have heard this phrase many times to describe in laymen’s terms the purpose of this program, and have used it myself.

diverse religious and non-religious traditions and values systems can be rich fodder for all parties involved in inspiring different ways of responding to a common moral problem. For example, global childhood vaccine programs are supported by a variety of religious and secular organizations, and while they have different underlying commitments that motivate their work, they can be encouraged by each other's sources of inspiration as they work with a common purpose.

More specific than this prophetic vision of no more infants dying, in the particular case of racial disparities in infant mortality in Milwaukee, certain commitments from the Christian tradition stand out, which I will discuss in turn. First is a way of thinking about justice from within the Christian tradition that is contextual and can therefore adequately consider social determinants of health. Second, critiques of US bioethics from African Americans working in the sphere of bioethics are explored. Then, I will show how Christian ethical reflection on racism and White privilege offers up the practice of *metanoia* as a step toward interracial solidarity. Next, I will consider how the preferential option for the poor, within the tradition of liberation theology, provides grounding for considering social vulnerabilities in bioethical questions.<sup>55</sup> Finally, considering the Strong Baby Sanctuary Program as an important starting point for this project, I offer an overview of sanctuary practices, both biblically-based and in contemporary times, to determine what might be fruitful for retrieving from Christian tradition and practice. Each of these four approaches to Christian bioethical inquiry exemplifies the turn to social analysis that I find necessary for composing an ethical response to infant mortality.

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<sup>55</sup>Rooted in Catholic Social Teaching, the preferential option for the poor refers to God's siding throughout history with the poor and oppressed. Hebrew Bible and New Testament accounts underlying this principle include the Israelites' escape from Egypt (Exodus) and the Last Judgement (Matthew 25:40). The preferential option for the poor will be discussed further below.

## A Contextual Approach to Justice

A broad framework is necessary for adequately grasping the multilayered problem of infant mortality. Instead of turning to a universal theory of justice, I find it useful to approach the particular injustice of infant mortality inductively. Lebacqz offers a helpful approach in this regard. Following Lebacqz, instead of beginning with the concept of a just world or society and then measuring the situation against it, I begin with the determination that the current situation is unjust. Lebacqz both recognizes Christian complicity in perpetrating injustices throughout history to oppress individuals and groups, and finds it essential that Christians be committed to responding to these injustices. As I have discussed in Chapter One and will continue to discuss in this chapter, the racial disparity in infant mortality should be of particular concern to White Christians.

Lebacqz offers an important starting point for a Christian approach to justice. In her framework, we begin with identifying injustices that manifest in everyday life as “the only honest place to begin, given the realities of our world.”<sup>56</sup> She describes racism as “ethnic injustice,” a myth that denies personhood and purports “inferiority of other to justify their exclusion, discrimination, mistreatment, and ultimately their death.”<sup>57</sup> She notes that racism intersects with sexual injustice, political injustice, economic injustice, cultural injustice, and verbal injustice as they perpetuate the degradation, violence, exploitation, and dismissal of persons.<sup>58</sup> She further charges that “injustices feed each other,” and that “the result is a web of

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<sup>56</sup>Lebacqz, *Justice in an Unjust World*, 11.

<sup>57</sup>*Ibid.*, 17.

<sup>58</sup>*Ibid.*, 17-35.



injustice that ensnares and destroys those within it.”<sup>59</sup> I cannot help but think of some of my collaborators and how their lives, each in its own way, are tangled up in webs of injustice.

Lebacqz offers the following foundations for a Christian approach to justice: “a historical perspective on injustice, the use of narrative, biblical stories as illustrative, and a willingness to be contextual.”<sup>60</sup> My project draws from these foundations by taking stock of the social realities in Milwaukee and using ethnography to gain a glimpse into the particular lives and beliefs of my collaborators. While I identify core Christian commitments instead of specifically focusing on biblical stories, Scripture does play a role in shaping these commitments and how they attend to injustice.

Finally, Lebacqz’s framework is an important push back against what she sees as more narrow theories of distributive justice that focus primarily on the giving to each according to what is “due”, required, or needed. Ultimately concerned with justice in the context of right relationship with God, self and neighbor, and responsibility to one another through covenant, Lebacqz offers a much richer concept of justice than a concern for distribution of resources. As Lebacqz asserts, “If racism is a reality in our world then justice cannot consist simply in giving to each other according to ‘need.’”<sup>61</sup> Indeed, while my collaborators have unmet basic needs like adequate housing, safe neighborhoods, transportation, and child care, they also identify larger injustices of being treated as second class citizens. Lebacqz’s understanding is rooted in restorative justice, where the focus of justice is not on giving to each her/his due but “on

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<sup>59</sup>Ibid., 35.

<sup>60</sup>Ibid., 154.

<sup>61</sup>Ibid., 151.

restoring the bases for a genuine human community of liberty and equality.”<sup>62</sup> This concept of justice resonates with Harvey’s reparations paradigm discussed below. In all, this contextualized approach to justice is a good fit for addressing infant mortality from a Christian bioethical perspective that is attentive to social realities and particular stories.

### **African American Voices in US Bioethics**

Given the glaring disparity for Black women and infants within Milwaukee’s infant mortality rate, it is important to look particularly to reflections on the experiences of Black women and men.<sup>63</sup> There is a rich history of Black and African American scholars and activists speaking out against the status quo that ranks the health and wellbeing of those with darker skins as a secondary priority in relation to their lighter skinned counterparts. While historically these scholars have worked in fields including sociology, law, literature, theology, and medicine, more recently they have turned their pens to bioethics. Over the past thirty years, they have joined with others in their criticisms of pragmatic approaches to bioethics. Here are some key insights from African American scholars writing on modern issues in bioethics that are promising for a Christian bioethical approach to the problem of infant mortality.

Black and African American women have written prophetically on the intersection of race, class, and gender specific to pregnancy and motherhood. This lens can add a distinctive and necessary layer to a bioethics project that is attentive to these issues. Legal scholar Patricia J. Williams and womanist ethicist Kelly Brown Douglas (as well as many others) explicate the

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<sup>62</sup>Ibid., 128.

<sup>63</sup>I approach this issue from a social location of privilege as an educated white woman. I reflect more on how this privilege shapes my research in Chapter One and later in this chapter.

damage done to Black women by stereotypical tropes that lead the minds of the majority to view Black women as bad mothers. For example, Williams writes:

the “strong,” libidinally endowed Black woman is more often depicted as a kind of androgynous or even masculine force. Consistently denied any archetypal function as parenting her own children, she is relentlessly figured as not just a bad mother but one who seeks motherhood only as the “lazy” person’s escape from her true place, best measured by long years of impecunious servitude to others. This fearsome image of the poor Black teenage pregnant “welfare queen” has facilitated the removal of social benefits for all women: i.e., the replacement of traditional welfare programs with so-called workfare programs, as well as the denial of additional benefits to poor women who have children while on public assistance.<sup>64</sup>

Here, Williams points out how Black women are either blanketed as entirely unfit mothers, or usurped of their motherhood altogether. Douglas’s description of the “welfare queen” further calls out this poisonous stereotype: “Welfare mothers are characterized as promiscuous unmarried women who sit around, collect government checks and give birth to a lot of children.”<sup>65</sup> These stereotypes are powerful. They shape public perception and tangible funding and policy decisions that affect Black women in very concrete ways. Moreover, these stereotypes do not create room for the consideration of the social situation that may lead one to be a single mother who relies upon public assistance. By their salaciousness and inaccuracy, stereotypes draw attention away from the actual lives of individual Black women, where social factors related to chronic illness, disability, barriers to employment, safety, housing, and the lack of resources available to address these obstacles entangle them in webs of injustice. Without the necessary attention paid to social determinants, these caricatures woven into the unconscious

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<sup>64</sup>Williams, *Seeing a ColorBlind Future*, 57.

<sup>65</sup>Kelly Brown Douglas, *Sexuality and the Black Church: A Womanist Perspective* (Maryknoll: Orbis, 1999), 53.

mindset of Americans are left as unchallenged “norms” of Black mothers behaving badly. These stereotypes are very much alive and well today.

Legal scholar and public policy expert Dorothy Roberts reveals that it is not just stereotypes working to demonize African American mothers—policymakers are also culpable. She criticizes public health policies that demonize African American mothers and seek to control their reproductive agency through target birth control programs.<sup>66</sup> While the majority of recipients of public assistance are blue collar White folks, a larger percentage of Black folks than White folks receive welfare benefits.<sup>67</sup> Additionally, single female heads of households are more likely to benefit from public assistance than two-parent or single male heads of households.<sup>68</sup> Also, Black families participating in public assistance programs are more likely to meet the income eligibility guidelines for poverty than their working-class white counterparts receiving these same benefits.<sup>69</sup> Based on the complexities of these realities, when cuts are made to public assistance funding, Black families and especially Black children are hurt the most. Given the reality of a significant demographic shift in the next decades where White people will no longer be the majority, Roberts argues that “proposals designed to reduce the number of children born to poor parents are an attempt to fend off this threat to White people’s welfare, a threat that is

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<sup>66</sup>Roberts, *Killing the Black Body*.

<sup>67</sup>Tracy Jan, “The Biggest Beneficiaries of the Government Safety Net: Working-Class Whites,” *The Washington Post* (February 16, 2017), [https://www.washingtonpost.com/news/wonk/wp/2017/02/16/the-biggest-beneficiaries-of-the-government-safety-net-working-class-whites/?utm\\_term=.b3bf7a6276c8](https://www.washingtonpost.com/news/wonk/wp/2017/02/16/the-biggest-beneficiaries-of-the-government-safety-net-working-class-whites/?utm_term=.b3bf7a6276c8) (accessed September 12, 2018).

<sup>68</sup>United States Census Bureau, “Income and Poverty in the United States,” <https://www.census.gov/library/publications/2017/demo/p60-259.html> (accessed September 13, 2018).

<sup>69</sup>Ibid. United States Census Bureau, “21.3 Percent of US Population Participates in Government Assistance Programs Each Month,” <https://www.census.gov/newsroom/press-releases/2015/cb15-97.html> (accessed September 13, 2018).

specifically Black.”<sup>70</sup> In other words, Roberts contends that targeted birth control campaigns aimed toward Black women under the guise of reducing children in poverty is actually a tactic used to safeguard the safety net benefits of Whites living near poverty levels. It is of utmost importance for a White scholar like myself to remain cognizant of the volatile history and present day reality of embedded prejudices in talking about Black and African American mothering. Therefore, a bioethics that takes seriously the lens of African American experience and scholarship is essential.

Black and African American scholars have contributed greatly to methodological considerations for bioethics that can help keep these kinds of insights in the forefront of bioethical endeavors. As Jorge L.A. Garcia puts it, “What is important is not so much a medical ethics that is distinctive of African Americans as one that is faithful, informed by, and seriously responsive to important forms of experience characteristic of African Americans.”<sup>71</sup> This approach situates the contributions of Black and African American scholars as a special lens that can focus a bioethics framework in a way that is particular to the Black experience in the US. It makes room for the importance of contributions of scholars like Williams, Douglas, and Roberts above, whose fields intersect with bioethical concerns.

Indeed, Garcia posits that through this lens we will see seven core elements to an African American approach to bioethics:

A meaningfully African American medical ethics perspective... should be (a) antimajoritarian and antiutilitarian, b) antinstitutionist, and (c) distrustful of an “ethics of trust”; that it (d) regard the patient as the one with the decision to make; that it be (e)

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<sup>70</sup>Roberts, *Killing the Black Body*, 112.

<sup>71</sup>Jorge L.A. Garcia, “Revisiting African American Perspectives on Biomedical Ethics: Distinctiveness and Other Questions,” in Lawrence Prograis Jr. and Edmund D. Pellegrino eds., *African American Bioethics: Culture, Race, and Identity* (Washington, DC: Georgetown University Press, 2007), 3.

sympathetic toward families without romanticizing them; and that it remain (f) free from the bonds of scientism and (g) open to insights from religious faith... it (h) need not be beholden to the neutralist political liberalism that dominated elite political thought in the last century's final decades, which often revealed a strongly antireligious streak.<sup>72</sup>

While each of these elements provides important direction to US bioethics, some are especially relevant to this project. First, highlighting the role of religion and faith communities in bioethical deliberation stands out in two of these core insights. Second, the lens of “being distrustful of an ‘ethics of trust’” recalls the historical abuses against African Americans by those in positions of power who have incessantly told Black people, such as in the case of the PHS syphilis study, to trust them while at the same time violating their integrity and any foundation for such trust. Finally, to practice the imperative to “be sympathetic toward families without romanticizing them” allows us to contemplate the role social determinants of health play in women’s lives without overlooking their agency, and simultaneously then, their dignity and self-worth.<sup>73</sup> To be sure, Garcia’s other elements of an African American approach to bioethics inform this work in important ways as well, and are used to shape and critique insights from collaborators in the

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<sup>72</sup>Ibid., 4.

<sup>73</sup>While Garcia expresses the need for sympathy, working for racial justice needs responses that go beyond sympathy to empathy and compassion. Consider this helpful distinction between sympathy and empathy, as offered by Massingale citing racial activist Caleb Rosado: “[Rosado] describes sympathy as a *feeling* of sorrow for the plight of another, but one that is often from a stance of social distance or remove from the victim. It’s a sense of pity at another’s need, along with a response of “I’m-not-like-you.” Sympathy remains at the level of mere emotion. Empathy builds on this emotional response as there is not only sorrow but *identification* with the other in need. Empathy establishes ‘a bridge of identification’ with the other, enters his or her emotional sphere, and identifies with the pain. One sees how this plight could be one’s own. A popular way of saying this is, “There but for the grace of God go I.” Rosado says that out of empathy arises a ‘weeping with those who weep.’ Compassion is response of a different level. Here there is not only sorrow for and identification with, but *action* to meet the other’s need. Compassion acts to alleviate the suffering of another.” Caleb Rosado, “The Undergirding Factor is POWER: Toward an Understanding of Prejudice and Racism” (1997), [www.rosado.net](http://www.rosado.net), as cited in Massingale, *Racial Justice*, 115.

following chapters. As I turn now to Christian commitments important for this work, it is helpful to consider how these may resonate with Garcia's points (g) and (h) above.

What might a response to racial disparities in infant mortality look like from an approach that takes seriously and is informed by these insights and critiques from scholars of color? An example of such a project is the Philadelphia Maternity Care Coalition, which was successful in reducing infant mortality rates in the 1980s. Infant mortality rates were higher across the United States in all racial-ethnic categories than they are now at that time, and the particular interplay of health care access, government policies, and social class dynamics were shaped by the political climate of the era.: However, the actions undertaken by this coalition resonate with what could be possible through listening closely to the perspectives of African American scholarship and the lived experiences of Black women to help determine how to respond to racial health inequities:

Major accomplishments of the MCC were its strong advocacy and social support to communities of marginalized women. The trust the organization garnered from the affected communities fostered the women's self-empowerment process. Women felt they owned and held control over their health as opposed to it belonging to uncaring health systems. They learned to negotiate with health care systems as well as learned their rights as health care consumers. Once the momentum of education, support, and advocacy was started, the community became leaders in the process. The results were changes in both macro and micro systems surrounding the women. Ultimately, with this high touch, highly collaborative style of organizing; the women in the communities became self-empowered to seek and expect quality prenatal care.<sup>74</sup>

This collaborative approach with underrepresented women offers a model for the kind of work bioethicists interested in addressing the infant mortality crisis in Milwaukee can advocate for, and that local health care systems, policymakers, and churches can participate in together to forge a path toward justice for Black families.

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<sup>74</sup>Linda Maldonado, "Lessons in Community Health Activism: The Maternity Care Coalition, 1970-1990," *Family and Community Health* 37, no. 3 (2014 Jul-Sep): 212-222.

### **White Christian Anti-Racism<sup>75</sup> and *Metanoia***

The fact that I am a White Christian with a particular embodied privilege inevitably impacts how I view infant mortality in Milwaukee, as well as how I believe I and others like me ought to respond. As a well-educated person who works in a health care institution, I also benefit from socioeconomic privilege and a kind of bureaucratic hierarchical privilege as well. Though as a woman I have experienced some gender discrimination throughout my lifetime and therefore can empathize to a limited extent with others who have faced oppression, I also recognize that my collaborators face multiple other layers that compound their disadvantage in ways I cannot know. While I try to check my bias and understand my privilege, I know both still affect how I see the world and the opportunities that are open to me. By trying to keep this awareness in the forefront of my mind, I have learned to slow down, ask questions, reflect, be quiet and listen, and also not be afraid to speak up when the time is right. Inevitably, I blunder. At these moments, there is temptation to withdraw from this work to avoid the unease of being outside my comfort zone. Then I realize there is greater motivation to press onward, knowing that there is a need for White Christians like me to wrestle in the most attentive and responsible way with the question of how to engage in White Christian anti-racism.

Black Catholic theologian and ethicist Bryan Massingale presents key insights on race and privilege that should be of particular concern for White Christians. According to Massingale, racism is an underlying set of meanings and values attached to skin color that pervades the

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<sup>75</sup>I use the term White Christian anti-racism here to draw upon the kind of perspective needed to pursue the cause of interracial solidarity. While the goal of White Christian anti-racism surely is interracial solidarity, it is difficult to know or describe what interracial solidarity looks like. Also, the term interracial solidarity does less to prompt an ownership of action, as well as a demarcation of a kind of action. It is my hope that the term White Christian anti-racism names the players who are to act (White Christians), as well as the kind of action necessary (acts that check white privilege and counteract racism).



collective convictions, conventions, and practices of American life, and has interpersonal and systemic effects including the justification of White privilege.<sup>76</sup> He urges us to look past a “common sense” understanding of racism—where person A consciously or subconsciously treats person B differently because of their skin color—to become awakened to the systemic tangling of racism in the very fabric of who we are.<sup>77</sup> Drawing upon sociological and theological foundations, he describes racism as a culture, and uses religious language to talk about culture as a collective people’s “soul.”<sup>78</sup> He then makes the case that while Black people are indeed diverse in many ways, from their social status to their religion and beliefs to their musical tastes, there is a common thread of the “experience of racial prejudice, discrimination, rejection, and hostility—both subtle and overt—based upon the simple fact of our physical Blackness.”<sup>79</sup> Given this common experience, Massingale names “struggle” as the “soul” of Black culture.

In a recent interview, Massingale provides further reflection on how racism affects the depths of our humanity:

We can understand racism in various ways. We can understand it as a sociological issue, as a political issue; but at its deepest level, racism is a spiritual issue. Racism is a soul-sickness. Racism has become a spiritual cataract; it affects what we see and what we don’t see, whom we notice and whom we don’t notice, and it’s distorted our vision so that we don’t see what’s there in front of us.<sup>80</sup>

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<sup>76</sup>Massingale, *Racial Justice*, 1-2.

<sup>77</sup>*Ibid.*, 1, 13.

<sup>78</sup>*Ibid.*, 19-22. Massingale draws from Bernard Lonergan’s concept of culture to develop these insights.

<sup>79</sup>*Ibid.*, 19.

<sup>80</sup>Gretchen R Crowe, “Unpacking the ‘Soul-Sickness’ of Racism Shootings in Texas, Minnesota and Louisiana Raise Need for Engagement, Conversation, Conversion,” *Our Sunday Visitor Newsweekly* (July 13, 2016), <https://www.osv.com/OSVNewsweekly/Article/TabId/535/ArtMID/13567/ArticleID/20273/Unpacking-the-soul-sickness-of-racism.aspx> (accessed March 7, 2018).

In an affirmation of Massingale's insights, I would encourage White Christians to take ownership of how racism acts as a cataract for us, distorting our ability to recognize and respond to the human beings right in front of us who happen to have darker skin. I further suggest that for White Christians, privilege also clouds the spirit.

We cannot adequately speak of racism without considering privilege. In contrast to "struggle" as the "soul" of Black culture, Massingale builds the case that "privilege" is the "soul" of White culture. Again, Massingale turns to sociology and theology to present this concept. He quotes sociologists Feagin and Vera who observe, "Apparently, for most Whites, being White means rarely having to think about it."<sup>81</sup> Citing these and other experts, as well as the personal reflections of people on their Whiteness, Massingale contends:

the "soul" or essence of White culture is a worldview that—when it adverts to itself—sees itself as the measure of what is real, standard, normative, and/or normal. White culture is a perspective that measures, but is seldom measured; studies, but is rarely studied; analyzes, but is not often analyzed; evaluates, but is typically not evaluated.<sup>82</sup>

Here, Massingale calls out White people for their complacency with a status quo that is self-referential and completely apathetic to non-White experiences, which are judged as non-normative. In short, he puts his finger on the idiosyncratic and illogical underpinnings of what it means to be White.

Many White Christians may at first be uncomfortable with how much this description of the "soul" of White culture rings true. While White Christians can indeed be passionate about racial injustices, we may be less engaged in considering what it

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<sup>81</sup>Ibid., 22.

<sup>82</sup>Ibid.

means to be anti-racism from the particular location of someone who is White. Our own Whiteness, and the corresponding privilege, often remains un-interrogated. While it is incredibly important for White people to read and learn about racism, it is just as equally our duty to take ownership of not only a commitment to racial justice, but a particular commitment to interrogating White privilege and what it means to practice White anti-racism.

White anti-racism motivates and grounds this work. Jennifer Harvey and others are role models for White Christians to put their privilege to good use and participate in bringing about justice for the marginalized.<sup>83</sup> Harvey prods White Christians who long for racial reconciliation to recognize that repentance and repair must come first. She advocates for a reparations paradigm that “requires us to ask the question that seems unthinkable to many White Christians: that, without repentance and repair having come prior, why would we even assume interracial relations to be desirable or beneficial to Christians of color?”<sup>84</sup> Harvey contends that without this piece of apology and restoring relationships, we are foolish to believe that interracial solidarity and beloved community are possible.

In the context of infant mortality in Milwaukee, a reparations paradigm calls White Christians to slow down our unexamined eagerness to “help” and start by considering the role White privilege has played in creating this crisis. Indeed there is a specific racialized relationship

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<sup>83</sup>Jennifer Harvey and Karin A. Case, *Disrupting White Supremacy from Within* (Cleveland: The Pilgrim Press, 2008); Jennifer Harvey, *Dear White Christians: For Those Still Longing for Racial Reconciliation* (Grand Rapids: Eerdmans, 2014); Laurie M. Cassidy and Alex Mikulich, eds., *Interrupting White Privilege: Catholic Theologians Break the Silence* (Maryknoll: Orbis Books, 2012); Jon Nilson, *Hearing Past the Pain: Why White Catholic Theologians Need Black Theology* (Mahweh: Paulist Press, 2007).

<sup>84</sup>Harvey, *Dear White Christians*, 5.

between Black people and their White counterparts in the US given the history of chattel slavery, *de facto* segregation during Jim Crow, and the *de jure* segregation of the today.<sup>85</sup> How did Milwaukee become so segregated? Why are Black families more likely to live in poverty than White families? Further, it means that without this piece of historical and social consciousness, all of the good Christian work in the world will not change the ratio at which Black and White infants die. What might repentance and repair look like in a segregated city? How might bioethicists informed by realities of race and privilege contribute to reframing responses to infant mortality? Where do health care professionals, policymakers, and churches fit into the action plan? These are the questions Harvey might suggest as a starting place.

This is not to discourage White Christians in our quest for interracial solidarity.<sup>86</sup> As Catholic theologian Jon Nilson points out, “from Black theology’s very beginnings, Black theologians have summoned White theologians to collaborate with them in the work upon which the authenticity of Christian theology and the vitality of the church depend.”<sup>87</sup> Though inevitably this work is complex and wrought with missteps born of unconscious biases and miscommunications, the cost of not responding to the call of Black theologians and addressing racial prejudice is not worth the risk. We risk losing our identities—indeed, our very souls, in

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<sup>85</sup>See my discussion in Chapter One on Constraints on Moral Agency for more on segregation and disparities.

<sup>86</sup>Massingale uses the term interracial solidarity interchangeably with his own description of compassion, as well as a sociological term “transformative love.” Massingale states: “Such transformative love or interracial solidarity, what I have been call compassion, has the power to profoundly affect the racial attitudes—and even the very identity—of white Americans.” Massingale describes compassion as “a gut-wrenching response to human suffering and anguish that propels one to act beyond the limits of what is considered reasonable and acceptable,” and sees it as “an essential dimension of racial reconciliation and justice-making.” Massingale, *Racial Justice*, 118, 114.

<sup>87</sup>Nilson, *Hearing Past the Pain*, 48.

Massingale's language—as children of God and people of good will if we turn a blind eye to Black theologians' invitation.

White Christian anti-racism aims to enter into compassion with those targeted by racial discrimination and repair society by creating relationships built upon solidarity. What practices can lead us to interracial solidarity? Based on the opinions of the above scholars, it appears that we are too eager to jump to the solution rather than put in the hard work to get there. While Harvey's reparations paradigm does indeed take hard work, it is representative of who we are called to be and is necessary to confront what is at stake: the loss of more Black lives. Preparation for the journey ahead, as well as prioritizing first steps rather than focusing on the endgame, is therefore prudent and necessary. *Metanoia* is a helpful Christian practice that can be considered a step on the path toward reparations and interracial solidarity.

From the Greek verb *metanoein*, *metanoia* carries with it a variety of meanings including contrition, performing works of penance, conversion, and changing one's heart or views.<sup>88</sup> It is used throughout both the Hebrew Bible and the New Testament when sinners are called upon to change their ways. *Metanoia* carries with it the sense of a visceral and embodied transformation more so than an intellectual commitment. Massingale describes *metanoia* as “a deep conversion of heart.”<sup>89</sup> He draws upon Catholic theologian Bernard Lonergan's understanding of conversion, describing it as “a fundamental shift in one's paradigm of understanding, interpreting, and acting upon reality... Conversion implies a radical transformation of the subject

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<sup>88</sup>Stephan Richter, Stephan, *Metanoia: Christian Penance and Confession*, trans. Raymond T. Kelly (New York: Sheed and Ward, 1966), 11.

<sup>89</sup>Crowe, “Unpacking the 'Soul-Sickness'.”

and his or her relationships with self, others, and God.”<sup>90</sup> Both Massingale and Harvey agree that nothing short of *metanoia* will be able to foster the kind of interracial dialogue needed to confront the spiritual sickness of modern day racism.

Harvey calls our attention to the fact that Sunday mornings are the most racially segregated times in the US.<sup>91</sup> Black Christians mostly worship with Black Christians, and White Christians with White Christians. This recognition is important for White Christians, because it challenges the normativity of the White Christian experience. For example, if White Christians mostly feel safe while gathered for worship, and do not reflect on how racism and privilege are present in Christianity, we are likely to misinterpret racially motivated acts of violence as aberrations instead of a pattern of White supremacy and terrorism. Our privilege of never having to think about our Whiteness and enjoying the privilege of gathering together to worship blinds us from recognizing that this norm may not be shared by Black Christians—or other darker skinned people of faith—who may not feel so safe being gathered together in houses of worship. Instead of seeing White violence against Black bodies as isolated incidents, then, Harvey encourages White Christians to see them together as “a systemic reality in need of systemic change.”<sup>92</sup> Harvey reminds us of the gospel call to *metanoia* as a practice to prompt this kind of change.

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<sup>90</sup>Massingale, *Racial Justice*, 121.

<sup>91</sup>Harvey, *Dear White Christians*, 15.

<sup>92</sup>Indeed, the concept of *metanoia* becomes particularly relevant for White Christians as they consider adequate responses to racial violence and injustice. In the wake of the shooting of nine Black congregants by a White gunman in Charleston on June 17, 2015, Jennifer Harvey points out that while White Christians across the country responded with horror, grief, and outrage, these responses, while morally necessary, are insufficient.<sup>92</sup> To pass muster, White Christians must be able to recognize a pattern of White violence against communities of color, and ask themselves what this says about being White in the US today. Harvey’s response to the Charleston Massacre, in part, insists that White Christians own the fact that our experiences of Christianity are racialized.

For Harvey, *metanoia* is an imperative: “turn around!”, “change your ways!”, “repent!”

These admonishments complement and build upon the descriptions of *metanoia* above. She provides an example of what *metanoia* might look like for White Christians:

It’s time for White Christians to act: to listen carefully to how Black Americans describe what they know; to have a stark confrontation with ourselves about our own White experiences and passivity; and to move with the same faithfulness, creativity, and courage that Black communities in the United States have consistently modeled for us.<sup>93</sup>

This “stark confrontation with ourselves about our own White experiences and passivity” is at the heart of what *metanoia* means for White Christians seeking racial justice.

Harvey’s ordering above, while not necessarily meant to be rigid, is a helpful sequence.

*Metanoia* can happen as a result of deep listening to the experiences of Black people, which then leads to deep reflection on Whiteness, and finally complete the transformation by participating in movements for racial justice. This commitment to *metanoia* is essential in order to adequately address the racial differences in infant mortality in Milwaukee, America’s most segregated city.<sup>94</sup>

### **Preferential Option for the Poor and Vulnerable**

From within Christian traditions, Liberation theology and its central commitment to a particular concern for the poor and vulnerable are especially relevant for a Christian bioethics addressing infant mortality. A bit of historical context can help make the case for liberation theology as a good fit for this project. In the late 1960s and early 1970’s, a Peruvian Catholic

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Jennifer Harvey, “Outrage is Insufficient: Jennifer Harvey on Charleston,” <https://eerdword.com/2015/06/24/outrage-is-insufficient-jennifer-harvey-on-charleston/> (accessed November 11, 2018).

<sup>93</sup>Ibid.

<sup>94</sup>See the discussion of this in Chapter One.

priest and theologian named Gustavo Gutiérrez (often referred to as the Father of Latin American Liberation Theology) called out the very existence of poverty as sinful in and of itself. This condemnation came from his experiences working with the rural poor in Latin America and his realization that their entrapment in a cycle of poverty was a direct result of local and global wealth and power. He criticized social programs aimed at development that did not include the liberation of the poor from continued systematic oppression. For Gutiérrez, liberation in the here-and-now is inextricably tied to spiritual salvation.

A central commitment for liberation theology is the preferential option for the poor and vulnerable. The preferential option for the poor and vulnerable is based on an understanding of justice where in order for all to be treated according to their need, those whose needs are most often unmet must be put first. Lebacqz gives us a biblical account of God's siding with those cast out from society in order to show that the poor includes the socially oppressed as well as the economically impoverished. She succinctly states, "Because God hears and responds to the cries of the oppressed, because God loves the poor simply because they are poor, we are drawn to the inescapable conclusion that there must be a 'preferential option for the poor.'"<sup>95</sup> The Catholic pastoral letter *Economic Justice for All* declares that "the primary purpose of this special commitment to the poor is to enable them to become active participants in the life of society. It is to enable all persons to share in and contribute to the common good."<sup>96</sup> The preferential option

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<sup>95</sup>Lebacqz, *Justice in an Unjust World*, 74.

<sup>96</sup>United States Catholic Bishops, "Economic Justice for All: Pastoral Letter on Catholic Social Teaching and the US Economy," 1986, [http://www.usccb.org/upload/economic\\_justice\\_for\\_all.pdf](http://www.usccb.org/upload/economic_justice_for_all.pdf) (accessed January 20, 2017).



for the poor is a key expression of justice and the common good that, while rooted in Catholic social teaching, can resonate with all Christians and other people of good will.

James Cone, a founder of Black Liberation Theology, approaches liberation from a US context of unjust race relations.<sup>97</sup> He professes,

Black theology is a theology of liberation because it is a theology which arises from an identification with the oppressed Blacks of America, seeking to interpret the gospel of Jesus in the light of the Black condition. It believes that the liberation of the Black community *is* God's liberation.<sup>98</sup>

Cone emphasizes the liberation of Black communities who have been oppressed by White people, while Gutiérrez focuses on the liberation of the poor from the rich. What these theologians have in common is an understanding that God is on the side of the poor and oppressed, a method that prioritizes listening to and learning from the marginalized, and the proclamation that liberation is salvation.

Building from the groundwork laid by Cone and Gutiérrez, Peter Phan states that the purpose of liberation theology is to exclaim that “liberation is salvation:”

[I]n order to arrive at an understanding of what “liberation” means, liberation theologians start not from the Bible or tradition but from the data of oppression/liberation as the social sciences understand them. This sociological concept forms the first generality of their theological science. The theologian does not work *with* but *upon* the concept of “liberation” derived from sociological studies. In this way the social sciences as well as other human sciences form an intrinsic and constitutive and not an adventitious part of theology. The theologian's task is to transform, with the help of the properly theological concept of “salvation” (the third generality of “first theology” now functioning as the second generality of liberation theologies), the sociological concept of “liberation” (the third generality of sociology now functioning as the first generality of liberation

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<sup>97</sup>James Cone's, *A Black Theology of Liberation* (published in 1970) came out three years before Gutierrez's, *A Theology of Liberation* (published in 1973).

<sup>98</sup>James H. Cone, *A Black Theology of Liberation* (Maryknoll: Orbis Books, 1986), 5.

theologies) in such a way as to produce a theological theory that “liberation is salvation” (the third generality of liberation theologies).<sup>99</sup>

Here, Phan explains that liberation is concerned with the tangible needs of a people in the here-and-now. Theologians, for their part, work upon this understanding of the needs for liberation, and put it into conversation with what is meant by divine salvation. The result is to acclaim that “liberation is salvation”—that fulfilling the concrete needs of people constitutes participation in bringing about God’s plan for humanity.

Let us consider a concrete example of how this method can frame a response to infant mortality. We can see from the sociological analysis in Chapter One that to liberate Milwaukee families from the social conditions that foster a pattern of infant mortality, efforts to reduce prematurity are essential. The task of theologians, then, is to articulate that based on our commitment to the preferential option for the poor and vulnerable, efforts to reduce prematurity not only hold the promise of social well-being for Milwaukeeans, but also the fulfillment of the divine plan laid out in Isaiah’s prophecy. To bring about the end of racial disparities in infant mortality is to glimpse the reign of God in the here-and-now.

Thus, the preferential option for the poor is a fitting commitment for this project in many respects. The Strong Baby Sanctuary project includes partner churches that run the gamut of Christian denominations. Liberation theology has room for contributions from Catholic moral theology and its social justice tradition as well as Black, womanist and feminist theologies (not an exhaustive list, but to name a few that are most relevant for infant mortality) that have grown from its roots. Therefore, responses to injustices that are grounded in liberation theology have

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<sup>99</sup>Peter Phan, “Method in Liberation Theologies,” *Theological Studies* 61, no. 1 (March 2000): 57-58.

great potential to resonate with Strong Baby Sanctuary groups. Additionally, liberation theology's prioritization of the experiences of the poor and the vulnerable aligns it with major strands within sociology and anthropology, which can make its outcomes intelligible to secular partners who are used to being motivated by justice critiques from non-religious fields.

### **Sanctuary Practices**

As a prominent descriptor in the program's name, sanctuary is a Christian concept that occupies a central role in the Strong Baby Sanctuary Program. Sanctuary carries with it a history of churches and people of good will creating safe and sacred places for those who have been displaced and disenfranchised to seek refuge and be recognized as worthy of care. While this rich meaning of sanctuary can be mined for valuable contributions to the Strong Baby Sanctuary Program, it is also important to recognize how other interpretations of sanctuary may detract from understanding the program's purpose. Therefore, a conscientious and deliberate inquiry into what is worth retrieving from sanctuary practices will be necessary.

The term "sanctuary" has its roots in the Hebrew Bible. The Hebrew word *miqdas*, translated as "sanctuary" or "sacred space," is used to refer to many instantiations of holy articles and places. *Miqdas*, in the priestly tradition, refers to an article or object possessing sanctity. In its earliest uses, *miqdas* often refers to the tabernacle, or the portable, tented dwelling place of God that moved with the Israelites during their displacement from the time of the Exodus from Egypt until their resettling in Canaan. In other instances, *miqdas* refers to the tabernacle vessels, the entire temple complex (including structures outside the tent), all temples throughout the nation of Israel, and the great temple of Jerusalem. In post-biblical Hebrew, the term *bet miqdas*,

meaning “house of holiness,” became the prevalent term for temple.<sup>100</sup> Therefore from the beginning, sanctuary designates both sacred places and objects, and is not limited to a particular location within (or outside of) a place of worship. In a theological sense, sanctuary means sacred space, and is first used to describe the presence of God among God’s people.

Another well-known meaning of sanctuary is that of asylum, or refuge from the judgment of law. White pastor-activist Bill Kellermann informs us that the right of asylum was commonplace at the local alters of Yahweh in ancient Israel:

When worship was centralized under the deuteronomic reforms, the local shrines continued to function as places of refuge, and the cities were afforded a special vocation in that respect. The residents of these towns were charged with a rigorous task of protection, “lest innocent blood be shed” (Deuteronomy 19:10).<sup>101</sup>

Kellermann highlights how this practice of sanctuary was not circumscribed to the temple and surrounding area, but was considered valid as soon as a person entered a biblical “city of refuge.” He also points out that asylum is not unique to Jewish or Christian traditions; sanctuary and asylum were also recognized practices in Egypt, Syria, Greece, and Rome. This practice of sanctuary as a safe harbor for those accused of manslaughter and sentenced to death continued through the Middle Ages in Catholic and Protestant churches across Europe. One familiar literary instance is Esmeralda’s stay of sanctuary within the cathedral walls after being rescued from death by hanging in Victor Hugo’s *The Hunchback of Notre-Dame*.

The breadth of the term “sanctuary” in the Hebrew Bible is in contrast to the narrow understanding of sanctuary as a particular architectural space. If we were to take a look at

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<sup>100</sup>Menahem Haran, *Temples and Temple Service in Ancient Israel* (Winona Lake: Eisenbrauns, 1985), 14-15.

<sup>101</sup>Bill Kellermann, “The Hospitality of God: The Theological and Historical Meaning of Christian Sanctuary,” *Sojourners* 12, no. 4 (1983): 26.

blueprints of Christian churches, most often we would see “sanctuary” as designating the space around the altar. In contemporary use, some Christians may refer to the entire worship area as the sanctuary. Still, this understanding of sanctuary is not as encompassing as that of the original meaning. With this modern understanding, sanctuary does not then refer to the narthex, the fellowship hall, classrooms, kitchens, gardens, or other gathering places within and around the building. Yet these are precisely the places where sanctuary takes place as part of the Strong Baby Sanctuary Program.

There are other meanings of sanctuary that can also offer description and meaning to the Strong Baby Sanctuary Program. Consider the meaning sanctuary takes on when being voiced by oppressed people. Understood to mean a safe place set aside for those who have been displaced, sanctuary embodies that which oppressed peoples are seeking and struggling to find. Refugees, outcasts, and those with no safe place to hang their hats cry out, “Sanctuary!,” looking for a place set aside where they can belong. Sanctuary is a place where they can stop running, catch their breath, and receive respite. More than this, sanctuary comes to mean a place where a person can be recognized as having worth and the ability to contribute meaningfully to society. US. English literature scholar Nicole Waligora-Davis reminds us of the many time throughout history where African Americans have wrestled with identity and belonging amidst personal relationships and social institutions that deem them outsiders.<sup>102</sup> She shows that for African Americans, who for so long were formally denied citizenship and still face discrimination, “Sanctuary!” is a cry to be recognized as equally contributing and deserving citizens of the US.

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<sup>102</sup>Nicole A. Waligora-Davis, *Sanctuary: African Americans and Empire* (Oxford: Oxford University Press, 2011), xii.

An example of contemporary Christian practices of sanctuary can be found in something called the “sanctuary movement.” Anthropologist Susan Bibler Coutin describes the sanctuary movement of the 1980s as “congregations giving sanctuary to Salvadorans or Guatemalans at risk of being detained and deported by US Immigration and Naturalization Services (INS).”<sup>103</sup> Christians involved in the sanctuary movement facilitated the transportation of Salvadorans and Guatemalans who were facing human rights abuses in their countries to safe places in the United States. Those involved did everything from arranging caravans to providing social services to holding ecumenical worship services to helping detainees file for asylum.<sup>104</sup> Another comparison to be made with the sanctuary movement is to notice that the activists who were its leaders were in large part women.<sup>105</sup> The Strong Baby Sanctuary Program shares this common thread of being led by women.

Being clear about what is meant by sanctuary specifically in this project is important. There are at least two ways I can think of where the way the language of sanctuary or (similar language like safe haven) may become confused with other concepts of movements in contemporary society. The first is the coining of the term “sanctuary cities” to refer to places in the US that limit how local law enforcement can cooperate with federal immigration agents. In this context, select American cities are sanctuaries for undocumented immigrants and their families. It would be at least confusing, if not misleading, for a church to identify as a Strong Baby Sanctuary and have the community understand it as a place that assists foreign-born

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<sup>103</sup>Susan Bibler Coutin, *The Culture of Protest: Religious Activism and the US Sanctuary Movement* (London: Westview Press, 1993), 3.

<sup>104</sup>Ibid.

<sup>105</sup>Robin Lorentzen, *Women in the Sanctuary Movement* (Philadelphia: Temple University Press, 1991).

parents without documentation in avoiding deportation. The confusion mounts when considering the focus on babies; while possibly a valid social justice concern, it is not the focus of Strong Baby Sanctuaries to assist foreign-born babies with gaining citizenship.

Among those who work in health care, it will be especially important to draw a clear line between the language of sanctuary and that of safe haven. Those who work in health care abide by Safe Haven laws. Under the Wisconsin Safe Haven law, a parent may leave their unharmed newborn infant under 72 hours old with a police officer, 911 emergency medical staff person, or hospital staff member without fear of legal consequences.<sup>106</sup> Those of us who work in health care are trained on what to do if we are approached by someone wishing to relinquish their parental responsibilities and give up their baby for adoption. We are coached to accept the baby, not ask any personal information, but encourage the person to complete a short informational form about the infant, including race/ethnicity, information about the birth and delivery, and family health history.

Since the Strong Baby Sanctuary Program is absolutely not in the business of accepting children to be given up for adoption or in any way usurping the responsibility of the parent—indeed, oppositely, the program seeks to provide additional support so that parents can fulfill their responsibilities well—it is important that “sanctuary” is not taken to mean “place where infants can be given up for adoption.” Of course, if adoption were something a pregnant woman were considering, we would provide information and referrals for counseling; this is different than having the expressed purpose of taking in infants for whom parents can no longer provide

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<sup>106</sup>All 50 states have Safe Haven Laws. Interestingly, Safe Haven Laws are also called Baby Moses Laws. Wisconsin Department of Children and Families, “Safe Haven for Newborns Information,” <https://dcf.wisconsin.gov/cps/safehaven> (accessed January 15, 2017).

care. Since the terms “sanctuary” and “safe haven” may be considered to mean the same thing by the public, it will be important to draw a clear distinction between these two meanings. Despite these potentials for miscommunication, there is much in the Christian tradition around the practice of sanctuary that can be fruitful for inspiring moral imagination and action around infant mortality.

### **The Role of Ethnography in Christian Bioethics**

Since the early 2000’s in particular, scholars in Christian ethics and bioethics have brought qualitative methods to bear on Christian perspectives on health, race, and privilege.<sup>107</sup> For example, select Christian ethicists engage ethnographic methodologies to study how the lived experiences of people help them interpret the socio-cultural and religious dimensions of sickness and health. They rely on medical anthropology, sociology, and other interdisciplinary works to provide context to the questions they ask, and then dialogue with more traditional literature from within Christian ethics to develop theological contributions. Examples include studies that learn from patients, parents, and providers in a pediatric care setting,<sup>108</sup> married

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<sup>107</sup>As put by White Christian Social and Medical Ethicist Aana Marie Vigen, “the purpose of qualitative research, in an inductive approach, is to describe in textured detail what the researcher learns from his or her immersion in a particular context.” This method seeks neither to quantify a given reality nor compare it to another. Instead, an inductive approach begins in the street or in the hospital room and observes what is there. This learning then informs any subsequent formal analysis. Hypotheses grow out of work in the field. Only after digging deeply into a small section of the ground does an inductive approach move to a higher vantage point to survey a larger scene. Aana Marie Vigen, *Women, Ethics, and Inequality in U.S. Healthcare: “To Count among the Living”* (New York: Palgrave Macmillan, 2006).

<sup>108</sup>Richard B. Miller, *Children, Ethics, and Modern Medicine* (Bloomington: Indiana University Press, 2003).



women with HIV in Tanzania<sup>109</sup> and the United States;<sup>110</sup> Black and Latina women with cancer and their health care providers;<sup>111</sup> and patients at the end-of-life and their health care practitioners.<sup>112</sup> A core commitment of Christian ethicists doing ethnography is that wisdom does grow organically from lived experience that speaks to concepts of salvation—the good, the holy, or the sacred—in real life. This commitment to uncovering images of the sacred from voices not often listened to, including women most affected by infant mortality and those professionals and laypersons charged with their care, offers guidance for my project.

Ethnographic fieldwork is a distinctive way of knowing and being<sup>113</sup> that provides the opportunity to challenge and transform social worlds into texts that analyze and reconstruct people's lives and actions.<sup>114</sup> Translating literally as “writing about culture,” ethnography became a popular tool of sociologists in the 20<sup>th</sup> century as they attempted to provide “thick descriptions” of the social values, norms, and symbols of a given community of people.<sup>115</sup> Through ethnography, we can gain access to the ways people from diverse backgrounds

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<sup>109</sup>Melissa Browning, *Risky Marriage: HIV and Intimate Relationships in Tanzania* (Lanham: Lexington Books, 2014).

<sup>110</sup>Emily Reimer-Barry, *Catholic Theology of Marriage in the Era of HIV and AIDS: Marriage for Life* (Lanham: Lexington Books, 2015).

<sup>111</sup>Vigen, *Women, Ethics, and Inequality in U.S. Healthcare*.

<sup>112</sup>P. Lauritzen, “Adequate Images and Evil Imaginations: Ethnography, Ethics, and the End of Life,” in David H Smith, ed., *Caring Well: Religion, Narrative, and Health Care Ethics* (Louisville: Westminster John Knox Press, 2000).

<sup>113</sup>Narmala Halstad et al. *Knowing How to Know: Fieldwork and the Ethnographic Present* (Oxford: Berghahn, 2008).

<sup>114</sup>Paul Atkinson, *For Ethnography* (Los Angeles: SAGE Publications, 2015).

<sup>115</sup>Clifford James Geertz and George Marcus, eds., *Writing Culture: the Poetics and Politics of Ethnography* (Oakland: University of California Press, 1986).

understand and prioritize norms and values that matter to them. Said differently, ethnography is “a process of attentive study of, and learning from, people—their words, practices, traditions, experiences, memories, insights—in particular times and places in order to understand how they make meaning (cultural, religious, ethical) and what they can teach us.”<sup>116</sup> Ethnography allows researchers to enter into the daily lives of persons to learn how they navigate life’s milestones and construct normative meaning. Ethnography, then, is a fitting tool to explore the intersections of White culture, Black culture, and medical culture in relation to the problem of infant mortality in Milwaukee.

Ethnography is also a helpful tool for White anti-racism as a central Christian commitment. Womanist ethicist Emilie Townes alerted us to the fact that stories from the underside of history will not be popular and well-published, and may require listening in different places in order to be heard.<sup>117</sup> Putting her words into action led me to find myself in a church basement, a health department library, and a hospital cafeteria with conversation partners I would otherwise not be likely to meet. Taking seriously Massingale’s description of White privilege helped me remain cognizant of the power dynamics at play as a White researcher when speaking with Black collaborators. Massingale’s work also helped me to not lose heart when I felt utterly helpless to respond to stories of anguish. His explanation of the Christian practices lament and compassion show that listening to and hearing about someone else’s struggle, while not enough, is also necessary and important.

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<sup>116</sup>Christian Scharen and Aana Vigen, eds. *Ethnography as Christian Theology and Ethics* (New York: Continuum, 2011), 16.

<sup>117</sup>Townes, *Womanist Ethics*.

Ethnography also complements liberation theology and the preferential option for the poor and vulnerable. For those wary that interdisciplinary methods are inexact, consider Gutierrez's perspective:

The use of a variety of tools does not mean sacrificing depth of analysis; the point is only not to be simplistic but rather to insist on getting at the deepest causes of the situation, for this is what it means to be truly radical.<sup>118</sup>

Triangulating statistical data with moral analysis from Christian ethics and ethnographic interviews may seem messy, but it is absolutely necessary to uncovering the root causes of infant mortality. If it is radical to recognize that the old ways of addressing infant mortality are not working and that creative, nonlinear approaches are needed, so be it—a radical problem deserves a radical response.

Ethnography, then, is a fitting partner for work in Christian ethics, and in particular around biomedical questions. Medical anthropology is the study of health, illness, and healing through time and across cultural settings.<sup>119</sup> Applied medical anthropology often makes use of ethnographic methods and techniques to confront emerging public health problems.<sup>120</sup> Nurse ethnographers have helped show that discovering the salient beliefs and behaviors of patients enables nurses to better deliver culturally competent and ethical care.<sup>121</sup> Indeed, ethnography is also used to better understand how health care providers themselves practice medicine. The type

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<sup>118</sup>Gustavo Gutierrez, *A Theology of Liberation: History, Politics, and Salvation* (Maryknoll: Orbis Books), xxv.

<sup>119</sup>George M. Foster and Barbara Gallatin Anderson, *Medical Anthropology* (New York: John Wiley and Sons, 1978).

<sup>120</sup>Robert T. Trotter, II, "Applied Medical Anthropology: Praxis, Pragmatics, Politics, and Promises," in *A Companion to Medical Anthropology*, eds. Merrill Singer and Pamela I. Erickson (Malden: Wiley-Blackwell, 2011), 59.

<sup>121</sup>T. Tripp-Reimer et al., "Cultural Assessment, Content and Process," *Nursing Outlook* 32 (1984): 78-82.

of triangulation common to ethnography, where researchers integrate ethnographic interviews with participant observation and review of existing documents and quantitative studies, has been argued to be especially fitting to the goals of nursing.<sup>122</sup> Given my research aims, ethnography is a fitting tool for this project because it enables me to see the barriers to healthy pregnancies and births from the viewpoints of those women who are most at risk, and those volunteers and professionals who work daily to combat disproportionate infant mortality rates.

Ethnographic fieldwork is also inherently participatory: the researcher makes a personal and intellectual commitment to be observant, to take the role of the other, to listen, and to learn.<sup>123</sup> While ethnography began as a research method rooted in living with and learning from cultures distinct from the researcher's own, as a field it has grown to encompass methods that allow researchers to learn more from the diverse subcultures within their own societies.<sup>124</sup> Ethnography is distinct from other research methods because of its emphasis on the researcher's accountability to humbly step into the experience of another, cultivate critical self-awareness, collaborate with research subjects, and direct the outcomes of research in a way that fosters pragmatic solidarity.<sup>125</sup> Participant observation can also lead to participatory action, where the

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<sup>122</sup>Nurses are skilled at asking questions, listening, social interaction, interpret and observe on several levels, and are self-reflexive. Janice M. Roper and Jill Shapira, *Ethnography in Nursing Research* (Thousand Oaks: Sage Publications, Inc., 2000), 26-27.

<sup>123</sup>Atkinson, *For Ethnography*, 34-35.

<sup>124</sup>Richard E. Ocejo ed., *Ethnography and the City: Readings on Doing Urban Fieldwork* (New York: Routledge, 2013); Roger Sanjek, *Ethnography in Today's World: Color Full before Color Blind* (Philadelphia: University of Pennsylvania Press, 2014).

<sup>125</sup>Scharen and Vigen, *Ethnography as Christian Theology and Ethics*, 17-25.

researcher works alongside collaborators to engage in practices that stem from what has been learned through ethnographic exchange.<sup>126</sup>

Also incredibly important to the ethnographer's task is how she engages with the media that are produced; namely, transcripts of interviews, field notes, and audio-recordings. Atkinson argues that the ethnographer, like any researcher, utilizes particular literary conventions to construct narratives that are authentic.<sup>127</sup> It has been my duty as I've reflected upon the written and auditory voices of my collaborators to express as accurately as possible the worldviews and perspectives of my collaborators, through attentive listening and hearing, checking my biases, and offering the texts I pen over for my collaborators' conferral. It is with these commitments in mind that I first set out to conduct an ethnographic research study.

### **Study Design: Scope and Limits**

I first became involved in the Strong Baby Sanctuary Program as a steering committee member during my fellowship in clinical ethics at the Catholic hospital system. I was there when the leaders chose the name "Strong Baby Sanctuary," when they initially invited churches to be part of the program, and when they prepared members of these churches to be leaders of Strong Baby Sanctuaries. I experienced the real desire for collaboration among diverse partners—church-based and secular, Catholic and Baptist, etc.—as well as sometimes awkward conversations skirting around issues like birth control and abortion. I recognized the opportunity for dialogue about common theological underpinnings and commitments that could resonate with

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<sup>126</sup>Peter Reason and Hilary Bradbury, eds., *Handbook of Action Research: Participative Inquiry and Practice* (Thousand Oaks: Sage Publications Limited, 2001).

<sup>127</sup>Paul Atkinson, *The Ethnographic Imagination: Textual Constructions of Reality* (New York: Routledge, 1990), 9.

secular partners to better unify and guide the steering committee. I also identified the need to learn from Milwaukee women and health care providers about what role Strong Baby Sanctuaries could play in reducing infant mortality.

Before developing my research study, I met with various stakeholders in the Strong Baby Sanctuary Program. I asked many questions: I wanted to know what motivated them, what their goals were, why they believed in certain practices, and why they chose their name. I listened. I took preliminary input from various stakeholders—physicians, Strong Baby Sanctuary coordinators, and Milwaukee women—to devise and revise my study parameters. Then, along the way in the midst of my research, I asked my collaborators about their desires for the outcomes of this research and what they would like the other groups to know. Sharing the results of this project with my collaborators—and indeed, with larger audiences of their peers—will inevitably be a necessary component of how this research truly becomes participatory action.

Since then I have transitioned from a steering committee member to a Strong Baby Sanctuary leader at my home church. One of two ELCA Lutheran churches that are Strong Baby Sanctuaries, we are by far the most White and the furthest south—a testament to Milwaukee's segregation. My experiences coordinating our Strong Baby Sanctuary and leading our support group, I also draw from my own first-hand experience to shape this project. Establishing long-term relationships with women as we share the stresses and joys of pregnancy and mothering has been eye-opening, humbling, and fulfilling, and has contributed greatly to this work. I owe many of the key insights of these next chapters to the women I work with at my home church.

The hypothesis undergirding my study design is that through learning from Milwaukee women, their health care providers, and those involved in community health about how they

understand the causes and risk factors for infant mortality, churches will be able to lift up practices from their theological traditions that are fruitful for engaging in solidarity as they create sanctuaries for strong babies. Therefore, I engaged in ethnographic interviews<sup>1</sup>) to investigate the relationship between Christian practices and those public health practices that are successful in reducing infant mortality; and 2) to draw out and make explicit theo-ethical images and language in a tangible way that unites, inspires, and motivates communities around these successful practices as they work to reduce infant mortality and end racial disparities in infant mortality. To really understand the links and disconnects between the literature and real life, I decided that ethnographic interviews with those closest to the problem of infant mortality would most help me translate knowledge gained from statistical data into concrete practices that matter in individual women's lives and the lives of their families.

Initially, I planned to interview a group of 6-12 people made up of health care providers, community health workers, and church health liaisons. The health care providers were specified to be family medicine residents who practice obstetrics and their faculty members, obstetricians, neonatologists, or similar providers from local clinics and hospitals. The community health workers were to come from Catholic and secular health systems and the Milwaukee Health Department. While the inclusion criteria for these two cohorts were broad, I began recruitment with partners of the Strong Baby Sanctuary Program, which reflects the makeup of these collaborators. Strong Baby Sanctuary support group leaders were to make up the church health liaison cohort. While most of my meetings were one-on-one, I did meet with two women together who both served as their church's Strong Baby Sanctuary leaders. Overall, I met with two family medicine physicians who practice obstetrics and teach residents; two nurses and one

social worker who work for the Milwaukee Health Department; and three Strong Baby Sanctuary leaders.

My inclusion criteria narrowed my pool of potential collaborators to professionals and volunteers within these groups who have significant experience serving African American pregnant women, infants, and their families. I also sought to include those who were interested in discussing how socioeconomic factors and racism create barriers to healthy births and healthy infants. While still being demographically inclusive, each group serves a high number of Black women who are pregnant and/or have young children. I met them in like places including a church basement, a health center conference room, a shared doctor's office in a clinic, and a hospital cafeteria. I asked about barriers faced by the families they work with that are tied to socioeconomic factors like poverty, insurance, housing, and education. I also asked how racism is at play in the lives of pregnant women, infants, and families, and in the lives of the physicians and community health workers themselves, and how this presents challenges to providing care and support. I asked for best practices that, in their experience, help to mitigate the effects that socioeconomic disparity and racism can have on health. All interviews were in person, were audio recorded, and lasted about an hour.

I soon realized that not only would I need to talk to the people who are trying to eliminate disparities in infant mortality, but that I would need to balance these perspectives with those of the women whose lives are directly affected by infant mortality. To ensure that the voices of Milwaukee women of childbearing age were represented in this study, I held a focus group interview with women who are part of a Strong Baby Sanctuary support group. The purpose of this focus group was to learn from women about their experiences with pregnancy, infant care,



health care access, socioeconomic disparities, and racism. It was important to me to be able to “check” the experiences and stories I heard from health care providers, support group leaders, and public health workers with the lived experience of those women the former were attempting to help. On a Saturday afternoon in July 2017, I met with five women at their church for lunch, prayer, and a discussion about barriers and opportunities to maternal and infant health in their community. This focus group was also in person and audio-recorded.

A central goal of this project was to listen deeply to those whose insights on racial health disparities in infant mortality have been unheard or marginalized. Recognizing the uneven power I held as the researcher, I did my best to turn over some control of this project to my collaborators. In my recruitment process, I gave a concise yet clear description of my project, calling out that I would be asking questions about socioeconomic disparity and racism. This description was emailed out with the consent form to physicians at a clinic that serves primarily African American women, Public Health Department personnel, and Strong Baby Sanctuary leaders. I met my collaborators in places that were convenient for them. It was important to me that my participants self-selected. In all, I talked with seven Black women (four from the focus group, and three support group leaders), three White women (one support group leader from the focus group and three public health personnel), and two White men (both family medicine physicians who practice obstetrics and teach medical residents).

There are limits to this study. The small sample size inherent to my project means I cannot make any sweeping observations about what most members of any one of my cohorts thinks about a certain topic related to infant mortality. The open-ended nature of the questions I asked makes it so that while a robust discussion about inadequacies in housing occurred in one

conversation, there may not be other opinions from other collaborators to balance this view. My commitment to having collaborators self-select was a trade off in that I did not actively seek out a blend of collaborators that mirrored the racial and cultural diversity of our community. While I am sure there is incredible knowledge to be learned from interviews with many other Milwaukee women, health care providers, public health personnel, and Strong Baby Sanctuary leaders, time is an inevitable constraint. Each in its own small way, these limits provide shape and character to this study in a way that both allows it to be an important project in its own right as well as a recognition that further research on this topic is necessary.

This chapter has made a case for Christian commitments to ground and inform deliberation in bioethical questions such as infant mortality. In particular, I have shown how Christian commitments including the preferential option for the poor, White Christian anti-racism and *metanoia*, and sanctuary practices are fruitful for grounding responses to infant mortality. Additionally, I have offered ethnography as a fitting partner for Christian bioethics. These commitments have shaped the entirety of this project: from the study design, to the way I asked questions of and responded to my collaborators, to how I organized the main themes from our conversations and chose those issues for further research in order to lift up as important responses to infant mortality. In Chapters Three and Four, you will meet my collaborators, learn from their experiences, and consider how the Christian commitments named here can contextualize common themes and situate responses.

## CHAPTER THREE

### LISTENING TO A GROUP OF MILWAUKEE MOTHERS

To better understand Black infant mortality realities in Milwaukee, it is important to listen to those who are most affected by this disparity: Black mothers themselves. Other relevant insight is also gained by the thoughts and experiences of those who work daily to reduce infant mortality and the disparities therein. This chapter and the one that follows will address a focus question introduced in Chapter One: How do socioeconomic and racial/ethnic factors relate to infant mortality in the concrete lives of Black women, and what insights do they, along with those who work to reduce infant mortality, have for combating this disparity?

Indeed, a central goal of this work is to prioritize the words and experiences of Black women and mothers in Milwaukee. Facing discrimination and oppression at the intersection of race, class, and gender, it is not often that Black women living at or near the poverty level are afforded the privilege of being listened to when it comes to matters of health care policy and distribution of resources. To best honor these voices, I begin with their insights in this chapter. I initially considered first discussing insights learned from the ethnographic conversations with physicians, public health personnel, and church member perspectives in this chapter and then presenting Black mothers' perspectives as a foil in Chapter Four. This order would have—for the most part—followed the chronological order of my interviews, and offered a look at how professionals understand factors involved in infant mortality followed by how they may be missing some pieces. I ultimately chose against this approach. The sequencing of first listening

to the voices of those who inevitably have more power and a more stable social location, and *then* seeing what Black women have to say, seemed to be following rather than challenging the *status quo*. Therefore, in this chapter you will begin to see from the perspective of Black women what they think is contributing to infant mortality, and in the next, how the themes from their discussion are or are not present in how physicians, public health personnel, and church group leaders approach the problem.

This chapter introduces original ethnographic fieldwork that prioritizes Black women's thoughts and experiences related to infant and maternal health. Of course, Black women are not a monolithic group, and there is a diversity of experiences of being Black and female in Milwaukee. While the women I spoke with share a racial identity, gender, geographic location, and social status of mother, they have different life experiences, values, and perspectives. Therefore it follows that the insights of the collaborators to this project are wholly their own, and do not presume to speak for all Black mothers in Milwaukee. However, I will attempt to draw together similarities between collaborators and let their experiences speak truth to the numbers provided by the sociological data covered in Chapter One.

I began seeking out a Strong Baby support group to conduct a focus group with by sending an email to all of the leaders, asking for anyone interested to get in touch with me. After a few weeks of no responses, I began calling a few leaders to see whether they might be interested in allowing me to sit in on a meeting and ask a few questions.<sup>1</sup> Jo was the first leader

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<sup>1</sup>Previously that summer, I attended a panel presentation on infant mortality in Chicago where one of the panelists had done community outreach work to gain a better understanding of the barriers to women's and infant health in the Chicago neighborhoods. I approached her after the discussion, told her about my focus group, and asked her thoughts on what kinds of questions I should ask. She gave me the advice to make the questions broad and open-ended, and keep them to a minimum. I actually took my first question directly from her: What are the barriers

to return my call. She is the parish nurse at an Evangelical Lutheran Church in America congregation in Milwaukee's inner-city. Though I did not know her well, I remembered Jo from some of our Strong Baby Sanctuary program meetings. After I explained my project and the kinds of questions I would like to ask, she invited me to attend their July Strong Baby Sanctuary support group meeting. We spoke again in advance of the meeting, and she let me know there would be a lunch first, and then she would turn it over to me to start the focus group. Jo took care of informing the members ahead of time that the focus group would be taking place. The focus group was in the middle of our time together and took about 75 minutes, and in all the meeting took about two hours from the start of lunch through to the closing prayer. Since that meeting, I have seen Jo again at Strong Baby Sanctuary program meetings. I also met with her once for lunch, where I provided her with five copies of a draft of this chapter, one for each of the focus group participants, each with a cover letter including my contact information for any comments or follow up. Jo was in touch with some—but not all—of the women who participated, and said she would do her best to distribute the chapter drafts. At this point, I have not heard any feedback from this group. Jo mentioned she would like me to return to the group to discuss some of my research, which I replied I would be happy to do, and while we have not scheduled a time yet, I continue to follow up with her.

Two hours is not enough to learn the entirety of a woman's life story. Since I was meeting all but one of the women in the group for the first time, my outsider status most likely had some effect on how they delivered their stories and chose which experiences to share. I

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to women and infant health in your community? The other two questions I asked were: How are these barriers related to infant mortality? What is needed to improve women's and infant health in your community?

introduced myself as a researcher and a fellow Strong Baby Sanctuary group leader, both of which inevitably shaped our interactions. Nevertheless, the stories and experiences the collaborators to this project did choose to share during our hour and fifteen minute focus group contain serious accounts of some of their life events and thoughtful contributions to the dialogue on women's and infant health. Remembering that what follows are not exhaustive profiles of the collaborators to this project, but rather glimpses into their thoughts and experiences, need not take away from the richness of what they did share and its relevance for moral discussions about infant mortality.

Together, the collaborators to this project were a group of two nurses (also grandmothers) who ran the program, two mothers from the community, and another grandmother and church member who joins the group from time to time. What follows is a careful attempt to represent key themes that emerged during our conversation. First is a discussion of the visceral experiences the collaborators to this project shared of violence and stress in their daily lives. The next theme concerns being made to feel “less than,” especially in situations steeped in social, bureaucratic, and institutional hierarchy. The final theme considers how faith and resiliency—lived out through everyday experiences of mothering and bonding with other women—play an important role in ameliorating stress and demoralization. This chapter concludes with reflections on how the collaborators to this project alluded throughout our discussion to moral agency, which, while at times constrained by many factors, was highly regarded as an important part of personal self-determination and choice. Before diving into these themes, the stage of our discussion within the church and surrounding neighborhood will be set, and each collaborator will be briefly introduced. Through reflecting on the words of the collaborators to this project, I

intend to present a nuanced discussion of how a group of women in Milwaukee understand barriers to and opportunities for maternal and infant health.

### **Breaking Bread: Five Introductions**

On a sunny Saturday afternoon in July, I parked in front of a prominent Cream City brick building anchoring the corner of a residential block. Neighbors stood and rested on their front porches rather than inside, talking with one another or just trying to enjoy the breeze. It was hot. Near the main entrance, the words Evangelical Lutheran Church in America designated the church's denomination. I entered through a side door with a large Strong Baby Sanctuary poster on it that led directly into the church basement. I was greeted by Gaia Earth<sup>2</sup> and Jo,<sup>3</sup> the two nurses who ran this particular meeting. A lunch of hot dogs, baked beans, and fresh fruit and veggies had been set out potluck-style next to folding tables and chairs in a U-shaped arrangement. On these tables set festive centerpieces as well as framed snapshots of pregnant women and mothers who had attended the last meeting. A table with infant clothes and other baby items was nearby. We were soon joined by a few more women and their children.

After everyone had arrived, we said a prayer and went through the buffet line. As we ate together, I got to learn a little about each of the women present, and then fuller pieces of their life stories as our discussion progressed. I learned that Gaia, who had initially greeted me, grew up in this neighborhood. Gaia is a public school nurse, in addition to running her own business as a life coach. She identifies as a Black woman, is a mother and a grandmother. Gaia's smile is inviting,

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<sup>2</sup>All names in this chapter are pseudonyms chosen by collaborators. Gaia Earth, focus group interview by author, Milwaukee, WI, July 29, 2017.

<sup>3</sup>Jo, focus group interview by author, Milwaukee, WI, July 29, 2017. Jo chose a first name only.

her voice is light and airy. She is passionate about helping women discover their “divine feminine energy.”

Jo is the other support group coordinator, and the only other White woman besides me in a room of women with multiple shades of brown skin. She is a parish nurse at the church and has worked in the African American community in Milwaukee for over twenty years. Jo’s calling is to guide and mentor women to find strength in their relationship with God and the example of Jesus Christ. She is sharply critical of the many ways society divides people, especially by race and by education, lamenting how division limits everyone’s ability to fully flourish as a human being. Jo, too, is a mother and a grandmother.

Marvelous Woman,<sup>4</sup> a self-identified African American mother and grandmother, has worked at the church for over twenty years. She has lived in the neighborhood surrounding the church all her life, and has seen how the myriad social ills around her have fomented joblessness, violence, housing struggles, and family instability. Marvelous thinks we need more women gathering in the churches to help each other deal with the hardships they face. Marvelous brings a spirit of generational wisdom to the conversation.

Victoria Jefferson<sup>5</sup> identifies as a Black woman and is the mother of six children. Victoria grew up in Milwaukee, has lived in the South for the past nine-and-a-half years, and has recently moved back to Milwaukee. She shared that God is her motivation to keep pushing forward as she strives to present good role models to her children and look for teachable moments in everyday experiences with them. Victoria considers herself blessed to be on a

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<sup>4</sup>Marvelous Woman, focus group interview by author, Milwaukee, WI, July 29, 2017.

<sup>5</sup>Victoria Jefferson, focus group interview by author, Milwaukee, WI, July 29, 2017.



journey toward a better life for herself and her children. Her two-week old daughter stays with her during our meeting while her other children are cared for by a woman of the church, along with Monet's daughter.

Monet Washington<sup>6</sup> is the youngest woman in the group. She identifies as a Black woman and is the mother of a one-year-old daughter. Monet's daughter was content to sit in Monet's lap all through lunch and then clung to her legs before finally being coaxed to go play with the other children. Monet has been attending this church since she was a girl herself and has been a part of this particular group for the past year-and-a-half. Reserved and soft-spoken, Monet believes that women can help each other through their struggles by sharing life stories, saying "We don't have to keep on going through this. We can move on."

As we finished eating, the church member providing childcare that day escorted Victoria and Monet's children to a different area of the church so the moms could have some dedicated time to spend talking with each other. The exception was Victoria's newborn, who snoozed silently in her stroller.

### **"A Culture that's Very Concentrated Here"**

I began our discussion by asking the collaborators to this project what they believed to be the biggest barriers to health for women in their community. A conversation began about nutrition. Marvelous shared her opinion that even if they were raised eating unhealthily, women know what they need to eat to be healthy, but some make unhealthy choices. Victoria agreed, saying there are a lot of programs helping people to eat healthy, and that she has put into practice what she's learned by being a healthy eating role model to her children. Gaia had a slightly

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<sup>6</sup>Monet Washington, focus group interview by author, Milwaukee, WI, July 29, 2017.

different take on barriers to health. While she agreed that there are steps women can take to eat healthier, she shared that “it’s hard to put it into practice when that’s all you see.” In Gaia’s mind, “[W]hat it boils down to is that we live in a culture that’s very concentrated here in the ’06. If that’s all you surround yourself with, and that’s what you see, somewhere along the line, we started to devalue people, and people have bought into it.” By “the ’06,” Gaia is referring to the 53206 zip code area, where she lives, works, and worships. This area, made up of the Arlington Heights, Bouchert Fields, and North Division neighborhoods, has high rates of crime and poverty. It is also highly segregated: according to recent estimates, 94.7% of people living in this area identify as Black or African American.<sup>7</sup>

What social realities shape this community?<sup>8</sup> Consider these sobering statistics: only 26% of working-age men in the area are employed, the poverty rate for children is 66%, and 64% of families are single-parent families headed by women. There is also a staggering lack of resources in the area:

There are no public libraries in 53206. No major parks. No Walmart, Kohl’s, Home Depot or Ace Hardware. No prominent restaurants, not even a McDonald’s, Wendy’s or Burger King. No Jewel-Osco, Sentry, Aldi or Pick ’n Save, with only a small Lena’s grocery off Fond du Lac and Meinecke. Child care centers, which have a median hourly wage of \$8.64, are the fastest-growing business. Social service agencies have made a commitment to the area, but charity is not an economic development strategy.<sup>9</sup>

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<sup>7</sup>95.9% of people in this area identify as Black or African American alone or in combination with one or more other races. 2.2% of people identify as White. 2.7% identify as Hispanic or Latino, with 2.2% of these identifying as Mexican. For more detail, see ACS Demographic and Housing Estimates 2012-2016 American Community Survey 5-year Estimates ZCTA5 53206, United States Census Bureau, <https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=CF> (accessed January 29, 2018).

<sup>8</sup>For information beyond this discussion, see the documentary film *Milwaukee 53206*, Mass Incarceration Project, LLC, 2018, <https://www.milwaukee53206.com/>

<sup>9</sup>Barbara Miner, “A Closer Look at Milwaukee Zip Code 53206,” *Milwaukee Magazine*, January 28, 2015, <https://www.milwaukeeemag.com/milwaukee-zip-code-53206/>

These realities complicate securing basic needs like a way to make a living and being able to put nutritious meals on the table. There are other consequences as well: a truncation of public life, limited safe spaces to gather, and a question raised of whether these neighbors have been abandoned by the rest of Milwaukeeans.<sup>10</sup>

Gaia's words "we started to devalue people, and people have bought into it," speak to feelings of low self-esteem and unworthiness she perceives among her neighbors. Put into context with the lack of social resources in the area, there appears to be a cyclical relationship between feeling uncared for and feeling unworthy of care. This devaluation of peers and self, points to an epidemic of negative self-esteem that is largely shaped by inadequate socioeconomic resources. I am inclined to see that absent public policy, institutional disengagement, and community apathy are the real "we" that started this cycle, affecting both how some in this neighborhood see themselves and how they are seen by others.

As we continued our discussion, the collaborators to this project expanded upon this sense of devaluation felt by women in their neighborhood. As they added to the experiences and stories of one another, three key themes materialized. These included violence and stress; social and institutional hierarchy and feeling "less than"; and faith and resiliency. While the first two came about in answering my question about barriers to women's and infant health, the third emerged not as a direct answer to a question. Rather, faith and resiliency seemed to weave through stories of immense suffering so integrally that it appeared impossible to discuss hardship without also acknowledging sources of personal strength. I say this here to point out that while I

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<sup>10</sup>While this area has highly disproportionate rates of poverty, crime, and incarceration, there are also many people who stabilize this community by being home owners who work as educators, lawyers, and in other professions who have lived in this community safely and healthily for decades.

distill each theme in sequence, during our conversation there was much overlapping, especially when it came to faith and resiliency. Each theme is also complexly related to the particular ways race, class, and gender shape each of the women's lives.

### **Violence and Stress**

Violence is rampant in Milwaukee. According to the most recently available data, in 2015, the FBI reported 1,596.1 violent crimes per 100,000 people in Milwaukee, as well as 145 murders that year. This reality led to Milwaukee being named as America's fifth most dangerous city in 2016.<sup>11</sup> More than half of Milwaukee men in their 30's and 40's have spent time in jail or prison. These statistics are compounded in the neighborhood surrounding the church: in that zip code area alone, 62% of Black men are incarcerated, making it the ZIP code area with the highest Black male incarceration rate in the United States.<sup>12</sup>

Violence emerged as the predominant theme that the collaborators to this project identified as a barrier to healthy women and babies. Each woman around the table shared at least one experience of herself or a close friend or family member being physically attacked or feeling in fear for her physical safety. Gaia's family has experienced the effects of violence and poverty in her neighborhood firsthand: her son has been shot twice, and her daughter has been the victim of a car-jacking. Victoria has been robbed at knife point and has seen a bullet whiz past her son's head. Jo has been warned by a Black colleague that as a White woman, she should not sit alone on the church steps—a place she has worked at for over twenty years. Marvelous cannot feel safe

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<sup>11</sup>Michael B. Sauter, Samuel Stebbins, and Thomas C. Frohlich, "The Most Dangerous Cities in America," *Milwaukee Journal Sentinel*, October 1, 2016, <https://www.jsonline.com/story/money/business/2016/10/01/most-dangerous-cities-america/91227778/>

<sup>12</sup>Pawasarat and Quinn, "Wisconsin's Mass Incarceration of African American Males."

from gunfire even in her own home, saying she has to “get on the floor now because we got shooting.”

Violence presents a constant threat to personal safety for those in the neighborhood. Jo shared that the church’s neighbors fear for their safety daily:

We have people who have lived in this neighborhood for 30, 40 years. They have their own homes. They own their own homes. They are scared to death to walk from their car into their house. They're afraid to sit in their living room because they hear gunshots. They gotta get down. I mean, we have people sitting in the insides of their homes who are being shot randomly, sitting down.

Milwaukeeans listening to this story may be nodding and recall the 2016 heart-wrenching fatal shooting of a little girl while sitting on her grandfather’s lap inside their house.<sup>13</sup>

More recently, a thirteen-year-old girl, who had previously received third-place honors in a city-wide essay contest for her paper decrying gun violence in Milwaukee, was shot and killed in her bedroom from outside gunfire.<sup>14</sup> Feeling safe in your own home as a baseline sense of security is decidedly not a given in certain Milwaukee neighborhoods.

Gaia shared this insight about the prevalence of violence in their community:

It's definitely not our upbringing, because it's happening only in this '06 ZIP code, so it has to be related to where we live. It has to be related to Milwaukee, to this ZIP code, in this area, and you know what that means? That means that being Black, living in this area, having some of the other issues that this area brings... but the number-one thing is: How many people, Black women in Madison, may have some of the same things with hypertension and things like that? That's based upon your food and your family, what you do, or your genes. But what we have here is—we can probably go around this table and ask, “How many people have you known in Milwaukee that have been shot or killed or raped or something?”

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<sup>13</sup>Jesse Garza, “5-year-old Girl Dies After Being Shot in Home,” *Milwaukee Journal Sentinel*, November 6, 2014, <http://archive.jsonline.com/news/milwaukee/child-shot-inside-milwaukee-home-b99386270z1-281861681.html>

<sup>14</sup>Annysa Johnson, “‘We Are in a State of Chaos’: Milwaukee Girl Cut Down by Gunfire Wrote of Senseless Violence,” *Milwaukee Journal Sentinel*, November 20, 2018, <https://www.jsonline.com/story/news/crime/2018/11/20/milwaukee-homicide-girl-13-dies-after-shots-fired-into-home/2064310002/>

Gaia points out that in Madison, Wisconsin's state capitol just 80 miles west of Milwaukee, Black women experience significantly less violence. According to the FBI, there were 832 instances of violent crime in Madison during 2016. In Milwaukee during the same year, there were 9,201 violent crimes committed.<sup>15</sup> While Milwaukee has over two times the population of Madison, it is staggering to see that violent crimes are almost ten times as prevalent. How does living in an area where violent crimes are high impact the daily lives of women?

Monet shared a personal story that shows the complex intersection of violence and health:

I'm seeing a counselor for my depression. I got anxiety and depression. I'm going through stuff like that. But I lost [a friend]. My friend got killed a long time ago, back in 2004. And it's still getting to me, because I see things that I see, and then it don't be there no more. Like, when I see it, I talk to my doctor about it. Like, I told him a lot. I've been through a lot, almost was dead. I've been hit two times. I've been in bad accidents. I almost was shot too. I got robbed and all that stuff. The main [person] I can talk to is my therapist, but I – stuff just really happened, and I was in jail for something that I didn't have nothing to do with. Someone shot a person, an ex over an ex, and I didn't have nothing to do with it, so they let me go and stuff, but I'm seeing a doctor for all this, and I'm just going through a lot.

Gun violence has had a serious and multifaceted effect on Monet's life. The experience of being shot at is traumatic itself. The added psycho-social-emotional impact of being imprisoned while innocent points to layers of bureaucracy that demands we pay attention to how the legal system of due process affects not only guilty parties. Monet's story makes clear the deep impact of not only experiencing violence oneself, but of losing loved ones to violence. Monet directly relates these experiences of violence to her anxiety

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<sup>15</sup>“Crime in the United States by Metropolitan Statistical Area, 2016,” Federal Bureau of Investigation, <https://ucr.fbi.gov/crime-in-the-u.s/2016/crime-in-the-u.s.-2016/tables/table-4> (accessed July 23, 2018).

and depression, and the reason she seeks mental health services. Her statement, “the main [person] I can talk to is my therapist,” shows trust in her health care provider. It may also point to the absence of social support from family and friends, and to the role further social support can play for women like Monet who have experienced so much violence.

Monet’s experiences of violence and suffering are not limited to the events above. She also shared that she has lost a baby, and has been in a physically abusive relationship. When reflecting on what messages she would like to spread to women in her community, she shared:

I lost a baby... it was hell, man. So I’d tell women that I know the same thing that I was going through, you all are going through it. We don’t have to keep on going through this. We can move on. Don’t let no man just tell you anything or abuse you—and I’ve been through abusive relationships, and I just let it go. I just said I couldn’t take it no more, about you putting your hand on me, and I was fighting back, but I couldn’t fight much back with him.

Losing a child is devastating, and has long-lasting effects on identity and mental health. While it was unclear to me the circumstances surrounding Monet’s baby’s death, I cannot help but think about how the layers of stress and violence she has experienced may have played a part.

Domestic violence, often kept hidden behind closed doors, is difficult to speak about—and to escape from. It is powerful that Monet shared her story of losing a baby and intimate partner violence as part of a message of solidarity with other women. She knows that other women are experiencing these kinds of suffering and violence too, and she wants them to know that there is hope of a way out and life on the other side.

I want to share a few quick notes on Monet’s story here, since her voice will play less of a role in the rest of the thematic developments. While Monet spoke least often during our time together, it was apparent that she risked her privacy, which she values highly, to share stories that raised visceral emotions. Money displayed vulnerability, bravery, and selflessness by

sharing her story in the hopes of helping other women. Given that Monet spent more time listening than any of the rest of us, it is essential to recognize that there is much more to her story as a person. Worth reflection as well is the unease presented by discussing intimate and distressing personal stories openly with me, a White woman she had just met. This reality of the research method presented itself to each woman differently, depending on how she personally negotiated sharing her stories with me and the group.

Gaia and Victoria also shared experiences of gun violence in their own lives and the lives of their loved ones. When considering how many people she has known who have experienced firsthand gun violence, Gaia said,

I've known six people between the age of five to 10, seven people, eight people 12 to 18, 20 year olds, 30 year olds. How many cousins? How many were relatives? All of us have extremely high numbers who have died and/or been shot. My son was shot twice when he was 13.

Victoria shared that her son was almost shot while in bed at night: "Literally, a bullet missed my son's head by about this much. We was laying down, asleep. It's like, 'Oh, my God, I have to grab the kids,' and it was like that's scary. That is terrifying."

In addition to gun violence, many of the women around the table had stories of other physical assaults. Monet shared that she'd been robbed. Gaia relayed stories of robberies and carjackings experienced by coworkers and relatives. Victoria recalled being mugged at knifepoint:

My last year, I was going to [high school], and I was being bad. I had skipped, but I was going to get me something to eat, 'cause I was in a half-day program. I was going to work, but I had left a little earlier than when I should've, and I had my purse like crossways over me, didn't have nothing in my purse. Mind you, I was a little tomboy. My mama made me wear a purse, and I had my little wallet, and I think I had a couple of dollars, not nothing big, maybe \$5.00, \$10.00, and a guy just was like, 'Let's make this easy.' He came up behind me, took a knife, and he said, 'Don't turn around until you count to 10,' and I counted to 30, 'cause I'm like, 'Somebody just took my purse, and they had a knife.'



Jo jumped in, saying “But you’re fearful for your life.” Victoria agreed, saying, “For a very, very long time, I did not even carry a purse, and believe me, I didn't leave school again, but it was just like, that does something to you. That traumatizes you, you know what I'm saying?”

The visceral feelings of having experienced violence were described differently by each collaborator. Victoria described it as trauma, feeling scared and terrified, and described her blood pressure going up. Monet talked about having to “go through it,” and having “been through a lot.” Jo described people being in fear and scared to death. Victoria, Gaia, Marvelous and Jo used the word “stress” or a variant to describe how they or others in the neighborhood often feel in response to violence. Sharing these stories brought on shudders and tears by some in the group.

Putting these experiences of violence into the context of barriers to health, Gaia named stress as the number one issue. “It's not happening in any other area, which brings it to the violence, and its stressful living. Our hearts are racing for dealing with the amount of stress, even though we don't say it.” She also said, “And you live with that though, and even though you don't talk about it, you own it. It's there every minute. It's going on in your heart. It's like a racing. It's like that anxiety.” Victoria agreed, saying:

My blood pressure kept going up... just being stressful, a lot of stuff that went on, thinking of this, thinking of that... I know everything that's going on, so I'm kind of scared... my fear is – the other day, I almost tripped and fell, trying to move my wallet. I mean, I really ain't got nothing in there, but... I don't want nobody knocking my babies down, thinking I got something in there, 'cause I really don't. They could have the wallet.

She is stressed out in part because of how the memory of being robbed at knife point so many years ago sticks with her. Now, it is not only herself she has to worry about, but her children too.

It makes sense that memories of violent events are recalled more often when you frequently encounter the same spaces where they took place. Gaia put it this way:

Even though you don't see it every day, we walk in it. It's like an umbrella, because I know somebody got shot on that corner. I walk past it. I drive past this street. I remember when my daughter's baby daddy died in the house that she lived in. I remember all these things. I came down Locust today, and I'm like, "Oh, I remember that. I remember I owned a property there, and all this went on." All those things are forever playing in your head.

This invisible umbrella of fear and anxiety follows Gaia everywhere she goes. Even on a hot July day, she can't close it up and put it away in order to enjoy the sun shining on her face. The stress has taken hold and made its dwelling place just over her shoulder. It is a constant reminder of the violent events of her past, and has a physiological effect just beneath her skin.

### **Social and Institutional Hierarchy and Feeling “Less Than”**

Another barrier to health for women and infants identified by the collaborators to this project was a sense of dehumanization characterized by the sentiment of “being made to feel less than.”<sup>16</sup> Other words used to describe this feeling included being demeaned, devalued, and made to feel unworthy or lose self-esteem. Women discussed encountering these feelings in situations included personal relationships, social services agencies, and health care. Indeed, many of these instances aligned with when women were faced with barriers to accessing health care and public services. For example, Monet shared that she is waiting on a hearing for SSI (disability assistance) and that she has been denied three times. I wonder if her being denied multiple times points to inadequate legal representation due to financial barriers or accessibility. While health care as an institution was discussed as one factor that made one feel “less than,” the collaborators to this project did not describe this in any personal relationships with health care professionals themselves. It could be that these women’s experiences with their health care professionals were

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<sup>16</sup>Discourse on recognition is relevant here, and another term for “being made to feel less than” as identified by my collaborators would also be misrecognition.

exceptional, or that they were not going to get into the details with me, who is admittedly part of the Strong Baby Sanctuary program and therefore representing health care in a sense.

Victoria spoke about feeling “less than” in her relationship with her children’s father. She expressed how her children sometimes repeat to her the negative things their father has said about her, and that he also demeans her in their presence:

I am more demeaned when my children are there than the law should even allow, and I don't ask for it. I really don't ask them to tell me what he's saying about me, but my youngest girl, she's close to me, and it's like, ‘Daddy said this about you,’ and... that is more stress to me.

It cannot feel good to have someone speak ill of you, especially to your children, and especially from the person who is co-parenting with you.

Victoria’s frustrations in this personal relationship with her children’s father are complicated by the fact that while they share custody, she does the majority of parenting. According to her,

He’s been on vacation since they [were young], but I’ve been there since day one, and my thing is like, ‘Okay, ‘cause now you finally woke up and smelled the roses and got your act together and tried to do something with your life, congratulations. Welcome to adulthood.’

At this point there is a burst of laughter, partly because of the sarcasm behind Victoria’s “wake up and smell the roses” riff. However, there was a sense that the laughter was also partly because the narrative of men as absentee parents is shared by others in the group, and laughter served to help those present commiserate about shared disappointments. Victoria continued:

You're not gonna make me feel less than, and you're not gonna call my phone and say, ‘I'm coming to pick up the kids in 20 minutes.’ Nope, have some respect... You've been disrespectful, very disrespectful to me, and I'm standing my ground as a woman. You don't have to see me as anything else. I'm not asking for nothing else from you, but see me as a woman – a mother of your children that's been here since day one.

For Victoria, being respected as an individual is tied to being respected as a woman and a mother. She finds it disrespectful when her children's father takes on the role of parent only when it is convenient for him, when she has been responsible for raising her children "from day one." When the years of love, care, and attention she has devoted to raising her children are not acknowledged by the person who is supposed to be her partner in parenting, it adds to this sense of "feeling less than."

When I asked Victoria about her doctor's office, she said:

They kind of knew my circumstances, homelessness and this, that, and the other, and they have been really supportive, and they asked me did I wanna speak with the – I think the social workers, and if they had resources, they were very open to give all that they had and reach out as much they possibly could.

Despite Victoria and her family's current situation of homelessness and living in a shelter with a two-week old baby, she appeared content with the way the social workers at her clinic offered her resources. At this point though, Jo interjected, in a way that complicates this picture. Jo said:

There are so many places out there that [say], 'Send people to us so we can help them.' And so, we refer people, okay, they can help with housing, they can help with this, they can help with that. So they give someone a list: 'Okay, this is where you can go to find housing. This is where you can go to do this.' And my perception is, someone needs to take someone's hand, and help them, mentor them, guide them. It's one thing to give you—say, 'Okay, call here, here, here, and here,' and then you face your six kids five minutes from then. Well, how are you going to—you know what I mean? How do we walk side by side with each other, and other women, to help them and to follow up?

Jo points out how impractical it might be for a single mother of six to get even five minutes of designated time to begin combing through a list of phone numbers. Her apparent exasperation when she delivered the above example shows frustration with a referral service that is detached from the lived realities of mothers. She uses the metaphor of someone's hand and walking "side

by side” to connote an alternative approach that is sensitive to a woman’s particular situation and can work within her context to get her what she needs.

Gaia had a similar condemnation of this kind of help via referral:

We have a large workforce working on problems we have in this area. It's just how they tend to go about it, and much of what the ladies are saying, giving 'em that sheet of paper, that's really not what they're – some people may do fine. She's right, I know. I ask them, ‘What would you need for me to do? I can sit here with you, and we'll start making some calls together.’ It's hard to do if your phone doesn't have a map or – and then you can click the button and say, ‘Get directions,’ or whatever, get directions while walking, on bus, or whatever, so some people don't know how to do that, and just to be able to help them with that. I think, yes, people are gathering up a lot of grant money for many problems that we have here in the city, but it's not being used in the way it should be, and that's really sad.

Like Jo, Gaia points out that the assistance that would actually help is not the list of numbers at all, but taking the time to care enough to make a practical effort to meet a woman’s need in the moment. This would require asking questions about whether her phone has internet access, what kinds of transportation works for her, and what her and her family’s schedule is like. Gaia does not see lack of financial or human resources to be the issue—instead, it’s how they’re being put to use.

This turn in the conversation caused Victoria to share a little more of her personal view on the limits of the referral approach:

I might not say the different words that you might say to better present me. You know what I’m saying? And that’s just like, I’m not bashing [agency] ‘cause they’re doing the best they can, but that’s what they did to me. They gave me a listing of all of the numbers in Wisconsin for housing, and that might be all that they can give women, but that was not—that might be, like, great help for this one woman, but to me... but I haven’t lived here in nine-and-a-half years. So I’m like, Where’s this? Where’s this? Where’s this?

At this point in her story, I remember Victoria smiling at the ridiculousness of the red tape she encountered while attempting to access housing resources from a local social services agency.

She is speaking to me, expressing her belief that I—a White woman with some health care savvy—might be able to better present her case on the phone to someone on the list of numbers. She is also expressing that while a list of numbers might be adequate for some women, it was not adequate for her, because she feels less able than a stranger to present her own situation over the phone. The irony that an agency that is supposed to be supporting women is actually making them feel less able to represent themselves is thick, at least in my view.

Victoria also points out how it can be the little things that make a difference between feeling “less than” and feeling respected. Though Victoria grew up in Milwaukee, she’s just recently moved back after almost 10 years away, and things have changed. She continued with a story about asking for directions that highlighted how the simple act of walking with someone can alleviate miscommunication and feeling like an outsider in a health care setting:

I was like, ‘This hospital is totally brand new to me. Like, I’m a brand-new person in Wisconsin, ‘cause I haven’t been here for so long,’ and actually, it took the security guard – ‘cause the lady was actually getting mad, ‘cause I’m literally talking to her like this. I’m talking to her, ‘Your directions are very good, but I still don’t know where you’re talking about.’

(By “talking to her like this,” Victoria spoke with a slow, soft, “let me break it down for you” tone, to show that she was conveying her appreciation but at the same time emphasizing that she needed better directions.)

It was actually that little restaurant when you first come in the first door. She was like, ‘Oh, the Garnish,’<sup>17</sup> and I was like, ‘The Garnish? What’s the Garnish?’ If I haven’t been here in 9 1/2 years, I’m like, ‘Is that outside the building and around the corner? Where is it at?’ And she was literally like, ‘You don’t know where the Garnish is?’ and I was like, ‘For one, calm down.’ ‘Cause I wasn’t being disrespectful to her. I was just letting her know like, ‘You’re doing all those nice directions, and I have no clue to what you’re even talking about,’ and I wasn’t being funny. I didn’t know. [A different woman,] the security guard, she got off her little station, and she said, ‘Ma’am, come with me. I’m gonna show

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<sup>17</sup>Name changed.

you exactly where it is.’ Now I know where the Garnish is, and it just took that compassion that the security guard had just – and it took, what, two seconds?

Two seconds was all Victoria was asking for to be heard, to feel respected. While many who work in health care settings attempt to treat patients with respect, it can take time and careful attention to work out what respect means for a particular person at that moment in time.

Gaia shared a perspective on public assistance programs that was unique among the group. When she was growing up, her mother, strongly independent and untrusting of the government, insisted that her family would not be recipients of aid programs. In Gaia’s words:

My mom said, ‘You want to be grown, and you want to do what grown people do? Then you need to go get a job,’ so I got a job at fourteen. ‘I couldn’t use Pampers, I couldn’t have WIC, and I couldn’t have welfare.’

By “pampers,” Gaia meant that her mom disapproved of disposable diapers, new at the time, and taught her to use cloth diapers. Instead of using WIC, the federally funded Women, Infants, and Children assistance program that provides a monthly allowance for approved healthy foods, her mom taught her how to budget her income and utilize church and neighborhood food pantries to make ends meet. Hers is a success story for self-sufficiency—she “made it,” she’s now a nurse, and she wants to help other women “make it” too.

Gaia presents her upbringing as formative in a positive way. It has made her wary of the way public assistance programs complicate a person’s agency and dependency. She shared, “What happens is you become a victim. It’s a link, and it’s something that happens to you, as to your self-esteem, your character, when you become part of these systems.” Here she points to how some government assistance programs can have a tendency to make those enrolled in these programs feel “less than.” Jo agreed, saying:

When you rely on someone, and someone really, in what they do, their whole idea is to make you feel less than or lower than, and when they do that, why do they do that? Because if you feel less than or unworthy or unqualified or unable, then they can say, 'But we'll do this for you,' and then they think, 'Oh,' but then they have charge of everything. They're in control of you. It's like you train your dog. You've got the trick. I give you the treat.

The power dynamics between women who qualify for public assistance and the gatekeepers to resources are tangible in this account. What better way to describe being made to feel “less than” than pointing out the similarity to how a dog is treated. It is important to point out here that while Gaia and Jo are advocates for women as moral actors in their own lives, it also doesn't seem to be their aim to deter women from accessing public assistance resources that meet their needs.

During our focus group conversation Jo and Gaia also pointed to barriers they saw affecting women's health perpetuated by the nursing profession itself. Jo spoke out against the different gradations of nursing licensures that privilege newly awarded Bachelor of Science in nursing (BSN) nurses over experienced licensed practicing nurses (LPNs):

Well, right, so because you don't have this certain level of education, you're put behind a desk. I deal with it all the time. I'm an RN. I'm a diploma nurse, okay? I don't have a bachelor's degree. I don't have a master's degree. I've been a nurse for 45 years. I've worked in such a variety of different areas of work. I cannot help to teach nursing students because I don't have an educational qualification...Hello? We live in a society where, okay, the more education you have, the better you are? Hello? The reason I was a good nurse to begin with was because my training happened in a hospital, hands on for three or four years, not in a book, and so it's – again, society creates these levels to make one feel “less than.” I've been made to feel “less than” because I don't have a bachelor's degree. I only have a diploma. Well, you know what? Some of what we are as human beings comes through our experience.

Here Jo points to a clear bureaucratic hierarchy present in both the nursing profession and health care system, where because she does not hold a bachelor's degree she cannot help teach nursing students. In some cases, she would be “put behind a desk” while a nurse with a bachelor's degree, but much less experience, is entrusted with patient care. Since only 7% of



registered nurses (including BSNs and LPNs) are men, this is overwhelmingly an issue of gender, too. A lens that takes into account both gender and class when considering the nursing profession must also point out that on average, male nurses earn over \$5,000 more annually than their female counterparts.<sup>18</sup>

While this delineation of the role of the LPN from the BSN is specific to education, as Jo notes, those labels represent a hierarchy that has been used to make her feel devalued. Jo's statement testifies to the reality that being made to feel "less than" is not only a shared experience among Black women living in this neighborhood. Jo has been made to feel less than by not being able to teach nursing students and by being overlooked for jobs when competing against a bachelor's degree nurse. The underlying message to Jo is that her 45 years of experience are not worthwhile to pass on to aspiring nurses, and that someone who has passed more tests will be better suited for patient care than her. While Jo can never fully grasp what it feels like to be Victoria, and made to feel "less than" in the particular ways she had, Jo can certainly empathize. Her feelings of being devalued because of her educational attainment can be a pathway for building empathy with mothers who have been implicitly told by those representing social institutions that they are not worthy of respect and care.

Jo continued, giving her perspective on why experience is such an important counterpart to education:

You can put all the educated people in a room and say, 'Help someone,' but if they don't have the ability to sit down, to walk, and to connect with people, you're not gonna accomplish what needs to be accomplished. So I believe society also has got to get some priorities in order to make a difference, and again, it goes back to relationships.

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<sup>18</sup>Ulrike Muench et al., "Salary Differences between Male and Female Registered Nurses in the United States," *Journal of the American Medical Association* 24, no. 31 (2005): 1265-1267.

Perhaps part of what Jo is trying to say is that medicine is a science, but it's also an art. A group of medical professionals can gather together and discuss the statistics related to infant and maternal health, but if they do not have the skills to listen to women, meet their needs where they are, and let these experiences inform practice change, not much can be hoped to be accomplished in terms of moving the needle on infant mortality.

While an important role of a health care professional is providing sound medical advice, without taking the time to listen to how a particular health concern affects a woman's daily life, how can you tailor your counseling and recommendations in a way that will be beneficial to her?

Gaia also spoke out about barriers presented by institutional components of nursing and health care. Picking up on Jo's statements about society getting some priorities in order, she shared this story about working as a parent educator at a public school:

I started working with the parent group there, great. January, we did a vision board. Women loved it. They came out. In February, I did affirmations. What is an affirmation? It's something that you declare that this is what you want in your life, and it has to be self-driven. It can't be, "My affirmation is my husband's gonna get his act together, and my children will not get suspended from school," so we did that. But after that time, my manager told me I can no longer do those programs because it's not evidence-based. I said, "Do you know what evidence based really means in the Black community? It means that you promised me you would give me a voucher if I listened to this program and answered these questions, and I give you your sheet of paper, and you give me my voucher, and I get up and leave." That's what evidence based is in my community, but these programs, when I got 25 moms and I had 125 for Mom's day, and you don't think that that's valuable?

Gaia points out the significant consequences of bureaucratic approach to community education that is not informed by the community itself. While Gaia's vision board and affirmations parent seminars were well-attended and growing, since it was not part of a curriculum and did not include an evaluation form, the impact did not matter to higher ups. Gaia even points to the

component of evaluation itself as a barrier, and that her programs were successful in gaining attendees even without offering a voucher in return. A step in the right direction would be to notice what programs like Gaia's are successful in the first place, and beginning from there as your "evidence" to build a best practice.

### **Faith and Resiliency**

When asked what helps to ameliorate these stressors and help women feel valued and claim their own agency, the collaborators to this project began discussing how they practice resiliency amidst adversity. Actually, even before I got to this question, many times the collaborators to this project could hardly finish telling a story of hardship without reflecting upon how they found the strength to make it through. As Victoria stated, "God is working on me, and he's blessing me and teaching me along the way, so I don't regret nothing that I went through. Everything I went through was a blessing."

Often, faith in God was an important part of this resiliency. The collaborators to this project spoke about how faith and resiliency were integral parts of womanhood and mothering. They also discussed how faith helped with anxiety, depression, and hopelessness. The collaborators to this project practiced their faith through reading Scripture, prayer, and attending the Strong Baby Sanctuary group. For example, Victoria relies on her faith, her small circle of support, her therapist, and the Strong Baby Support group when she feels depressed:

I haven't had any [postpartum depression], because like I say, my biggest thing that I'm leaning on right now is God, faith. That is the biggest thing that is keeping me going, 'cause like I say, way back when, I did fall in depression really, really hard, and I'm not trying to go back there. So like I say, reading my Bible, just like the little support that I do have, people that I can trust and talk with, I talk with them, so I try to stay open. Like I say, my therapist is a big help.... Yeah, just being open, letting it out, releasing it...Just like this type of setting, this is – I call this therapeutic. This is rejuvenating.

With a two-week-old infant to take care of, Victoria knows that the possibility of postpartum depression is real, so she's taking steps to also take care of herself. When her children's father asked her where she was going that day, she told him she had an important meeting. She told him,

This is the bettering of me, so I can take care of your children. If I'm not good, if I'm mentally out there, then I can't take care of them. I have to be right here. This is a good thing for me, rejuvenating mentally, spiritually.

Victoria presents a holistic view of wellbeing, where relationships with both God and medical professionals are important for mental and spiritual health.

For Victoria, caring for one's mental and spiritual health are important components of being a good mother. Comparing herself to her children's father, who has been in and out of their lives, she says, "I've been a mother since day one. I have not missed a beat with my children."

On raising her oldest son, she shared,

At the end of the day, I provided male role models that are positive and Godly role models for him, and ones that want to teach him the right way, and those influences are a man that I want my son to become, and I said, 'You need to become that.'

In addition to looking for Godly role models for her children, Victoria relies on her intuition to help her decide what is right for her children. She describes intuition in a way that is infused by the Holy Spirit:

You step out on that feeling, and that's that intuition feeling, 'cause you know what's right, and you know what's wrong... And I say it spiritually. I go off of what the Holy Spirit tells... It's like if I go and I'm making a decision, and it's like, "Lord, which one is the right direction for me to (go), or which way do you want me to go?" 'Cause I know he ain't gonna lead me no wrong way. He gonna lead me the right way, so that's what I do.

Here, Victoria also speaks to the power of prayer in the sense of a constant dialogue she engages in with the divine about matters of morality.

This kind of faith allows Victoria to be confident in her parenting even if it means that by doing the right thing, her children are more likely to “stand out” than “fit in”:

I'll be trying to teach them it's okay to be the one that's different from everybody else. You ain't gotta be like the whole crowd, and sometimes you're the one that's making the stand for everybody that might not be saying something. That you might be saying something that they might be thinking, so you know what I'm saying? Step out and be a leader sometimes, you know what I'm saying?

Not only is her message “it’s okay to be different,” but also “stand up for those who are outcast.” Here, she is pointing out the difficulty children can have with doing the right thing when it is unpopular. Victoria’s faith helps her be the kind of mother that prepares her children to be positive actors who respond with empathy and compassion to those who hurt.

One of the final questions I asked was about the messages these women would like to give to their peers in their community. Marvelous responded, “I'll say a lot of positivity and a lot of love. I'm there for you. Don't put so much stress on you, because when you put a lot of stress on you, then you stress your kids out.” During this discussion, Marvelous shared that after she had her first child, she “had six more kids, had five and lost one.” While I am not sure whether Marvelous had a miscarriage or a child that died in infancy or later, I do think it is important that she decided to share this intimate and painful detail about her life when talking about what can help other women. Like Monet, Marvelous believes that the church plays a vital role in having a safe space to share painful stories of grief and loss in order for women to build a sense of personal security and a support system. It is apparent that the women in this group care deeply for others in their community. They have compassion for those who experience the same levels of suffering, violence, stress, and disrespect that they encounter constantly.

The women I spoke with believe that meetings like theirs can help to ameliorate some of the stressors women face daily. According to Marvelous, “We need more women gathering in the churches.” Monet agreed—“It could help other women. I know it helps me.” Jo added on, “And as adult women, we need to be creating a space and support for those younger women that are coming behind us, and from a spiritual perspective, we need to really do that focused on God.” While increasing social and spiritual support is just one piece of the puzzle, along with improving socioeconomic conditions and counteracting implicit bias and structural racism, it is an essential component for women’s and infant health and needs to be supported and expanded.

### **Concluding Thoughts on Agency**

Throughout our conversation, the collaborators to this project continually told stories that were reflective upon women’s agency in situations where choices were limited or constrained. In many cases, instead of blaming poor health outcomes on a lack of support, resources, or something outside of individual control, the women I spoke with emphasized personal agency as an important foundation of moral action. While in their stories the moral agent inevitably bumped up against the jagged edges of constraints outside their control—including the prevalence of gun violence, abuse from romantic partners, and unhelpful hospital and social service staff, to name a few—in their retelling of their experiences, their moral agency was never usurped. It was especially important for the collaborators in this focus group to talk about how women take ownership of the choices they make that affect their health. Despite describing barriers to health and telling about hard times in general, the women I spoke with did not downplay their roles as moral agents in their own lives, though they may have moments of feeling hopeless or not in control.

At times I found myself wanting to contextualize the constraints around some behaviors that the collaborators to this project called out as unhealthy choices women make for themselves. At the beginning of our conversation, Marvelous gave an example while discussing unhealthy habits:

We eat unhealthy food. We drink unhealthy. We act unhealthy, and then we play the blame game. We get assistance and all of this other stuff, but we choose to use it unhealthily. And how we search for things like this, like Strong Baby Sanctuary, where we can get our baby some free clothes and all that stuff. But we as a people wanna just live free, that I can budget myself on this and budget myself on that. And when we as African Americans try to help one another budget themselves, they don't want that, but they get upset when it disappears from them, and we don't understand why we're not getting the help, and we already had the help in our hands. But we wanna turn around, and here we go again with the blame game. And so how we get a whole lot of stamps and so we wanna buy a \$24.00 steak, and that's just gonna feed one person, 'cause they're gonna do like this. It's big, but it goes like that.

Here, she highlights women's agency and reprimands those who do not budget adequately and then blame others for their limited choices. Victoria and Gaia agreed with Marvelous, and identified ways they have found to be able to cook modest, healthy meals on a limited income. My initial impression of the way this conversation was going was that the collaborators to this project were placing sole responsibility on the shoulders of the women in their community for their poor health, and were maybe unaware of how policies that affect access to healthy food constrain individual choices. What I then began to realize is that they were carving out an important role for individual agency as a cornerstone of women's participation in their own health and wellbeing. What I recognize now is that the collaborators to this project are well aware that physical health is intertwined with social, emotional, and spiritual health, and that while social constraints are inevitable, it is paramount to recognize that these barriers never erase a woman's moral agency.

At the same time, these conversations made it apparent to me that women could be better supported to affect positive changes for the betterment of their health if those with power took action to limit social constraints faced by women. What role might health care professionals and churches play in deconstructing these barriers? This question is taken up in the following chapter, when physicians, Milwaukee health department personnel, and Strong Baby Sanctuary leaders weigh in on how they see barriers and opportunities to confronting racial disparities in infant mortality. While many within this group are aware of the kinds of struggles women like the collaborators to this project in this chapter face in their daily lives, there appears to be room for growth in understanding of how intimately social determinants alter particular life stories. While being cognizant of social determinants of health, it is clear that, when compared to the thoughts and experiences shared in this chapter, health care professionals and church members have different opinions on which of these factors are most detrimental, causative, or easily addressed.



## CHAPTER FOUR

### CONVERSATIONS WITH HEALTH PROFESSIONALS AND CHURCH GROUP LEADERS

The Strong Baby Sanctuary program brings together distinct groups committed to eliminating health disparities for Black infants in Milwaukee. These groups include church members who lead Strong Baby Sanctuary support groups at their home churches, health care professionals employed by a Catholic health system who provide prenatal and obstetric care, and health professionals who work for the Milwaukee Health Department in areas related to infant health. Through ethnographic interviews, I met with three church support group leaders, two family medicine physicians who practice obstetrics and see pediatric patients, and three Health Department personnel to gain insight into how they understand the causes of infant mortality, barriers to health, and opportunities for eradicating racial health disparities.

To recruit collaborators for this set of interviews, I reached out to key contact people I had professional relationships with from each of the above mentioned groups. These included the program coordinator for the Strong Baby Sanctuary program, a Health Department nurse who was on the Strong Baby Sanctuary program steering committee, and a manager at the clinic affiliated with the Catholic health system. After discussing my project with each of them either in person or by phone, I sent them each an email, with a letter explaining my research study and the consent form attached.<sup>1</sup> They forwarded this email to their colleagues, and I received emails from three folks at the Milwaukee Health Department (Gail Sentry, Katy Lubner, and Claire

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<sup>1</sup>See Appendix A.

Smith) whom I had never met before to set up interview times. I also received an email from a physician (Greg Johnson) at the clinic who I knew previously from my fellowship, expressing his interest. Not hearing from anyone in the Strong Baby Sanctuary church leader group, I reached out to two women—one of whom (Mary Evans) I had known professionally for two years, another (Sister Faye) who I had spoken with a few times at Strong Baby Sanctuary program meetings. They both agreed to meet with me, and Sister Faye offered to bring along their co-leader, Missy, an idea that I welcomed. I also contacted another clinic physician I knew from my fellowship (Luke Williams) who agreed to be part of my study.<sup>2</sup>

What follows will be a small window into the experiences and insights of the collaborators to this project. Nevertheless, what they chose to share speaks to how those in their disciplines see and understand factors related to infant mortality. In my recruitment letter, I state,

I am currently looking to interview physicians and community health workers with experience serving pregnant African American women, infants, and their families who are interested in discussing how socioeconomic factors and racism create barriers to healthy births and healthy infants.<sup>3</sup>

Given that I was upfront about wanting to discuss how race, class, and gender affect the health of women and infants, we can make a few modest generalizations about the collaborators to this project. They were open to talking about these sensitive subjects, and possibly had done some personal reflection if not more formalized studying about the causes and impacts of racial disparities on health, and in particular, on infant mortality. Being attentive to these factors undoubtedly affected their experiences and how they shared them with me. However, being

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<sup>2</sup>The names introduced in this paragraph represent my research collaborators. More will be explained about how they are identified as they are introduced in subsequent paragraphs.

<sup>3</sup>Recruitment Letter, used by author, May 4, 2017, included in Appendix A.

attuned to the realities of institutional racism and socioeconomic disparities in Milwaukee and their effects on women and infants does not preclude one from, at times, succumbing to unconscious bias oneself. A common experience I had while talking with each of these collaborators is how the intersection of race, class, and gender often make the larger picture of infant mortality more complex.

These interviews were different from the focus group introduced in Chapter Three in many respects. Unlike the focus group, I had met all of the collaborators introduced in this chapter at least once, and had working relationships with some of them (which will be noted in-line or in footnotes as they are introduced).<sup>4</sup> Instead of a group meeting, these interviews were one-on-one, which allowed me to ask more questions in total and more follow up questions related to topics they brought up. The only exception is when I met with two church support group leaders who lead the same group together, the three of us sitting down for the interview. While I followed a similar set of twelve questions in each conversation, I took liberties to change around the order, skip questions, and probe further on some topics as important and relevant issues came up.<sup>5</sup>

Knowing there are inherent benefits and drawbacks to both the focus group model and the one-on-one interview model, I consciously chose the one-on-one model for this set of collaborators for an important reason. In my experience on the Strong Baby Sanctuary steering committee and as a church support group leader, I had intuited that there may be some

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<sup>4</sup>Comparatively, of the focus group participants, I had only met Jo previously. As mentioned in Chapter Three, Jo and I had met once or twice in passing during Strong Baby Sanctuary quarterly meetings at the sponsoring hospital.

<sup>5</sup>See Appendix B.

misunderstandings and criticisms harbored between the three groups represented. Issues like birth control come to mind, as I recall a Health Department representative being concerned about how health care professionals at a Catholic health system, as well as churches of varying denominations, would view providing information about contraceptive options. Safe sleep was another hot topic, where the Health Department's at times dogmatic teaching of the ABCS of safe sleep did not seem to match the approach of church support group leaders who often spoke about how this was not an issue when they were raising children. As you will see, these issues both came up in the one-on-one interviews. Through these interviews, I identified further differences in perspectives on these issues and others, including maternal agency, fatherhood involvement, and racial bias in health care and social services. What follows is an attempt to accurately represent these diverse perspectives, put them into conversation with relevant literature and one another, and draw some realizations about the moral meaning of the overlays and gaps between perspectives on infant health and death.

Therefore, the following sections discuss in depth multiple themes identified from conversations with the collaborators to this project. First, attention is given to public misunderstandings and apathy concerning infant mortality in Milwaukee. Next comes a discussion of the multiple barriers these professionals and lay persons find to supporting Milwaukee mothers—African American or Black mothers in particular—that highlights how things like medical paternalism, racial bias, White privilege, and lack of support for dads complicate moral decision making for pregnant women, their partners, and parents. This section concludes with a discussion of how health professionals and church group leaders may be giving mixed messages around family planning and infant death bereavement. Third, the collaborators

to this project share their insights on how we can support Milwaukee families and take steps toward solidarity, including thoughts on health policy and building trust in the patient-clinician relationship. These perspectives are good fodder for the analysis and recommendations to come in the next chapter. While robust, these three main themes are not exhaustive of the issues covered in our conversations, so before concluding the chapter I will touch on a few of the topics the collaborators to this project brought up that were not treated in detail, as well as give my reflections on what I did not hear.

### **Public Misunderstandings and Apathy Regarding Infant Mortality**

Mary Evans,<sup>6</sup> an African American parish nurse and Strong Baby Sanctuary program leader introduced in Chapter One, is concerned that the public does not actually understand the underlying factors causing infant mortality in Milwaukee. When I asked Mary specifically what White church members need to know about infant mortality in Milwaukee, she said:

Make sure you let them know it's not just women in poverty. 'Cause they'll say, 'Well then why are they in poverty, why are they having these babies that they can't take care of,' and 'They're the reason their babies are dying.' You have to shine the light [for] them, let them know that it's the same rate even for women that are professionals, married, and did everything right. Their babies are dying too. So it's just being African American in America that you have that risk factor of your baby dying.

Mary understands that for African American women in poverty and professional Black women alike, maternal behavior is not the root cause of infant mortality. However, she's skeptical that White churchgoers have this understanding, which points to the pernicious stereotype of unfit Black mothers at play. When I asked Mary whether she thinks White people are cognizant that infant mortality affects Black women of all socioeconomic classes, she responded:

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<sup>6</sup>Mary Evans [pseudonym chosen by collaborator], interviewed by author, Milwaukee, WI, June 5, 2017.

I don't think they know. And then when they hear about this co-sleeping, they go, 'Oh, they were sleeping with their baby.' 'Cause people always want to be able to say, 'I'm good, I'm alright. They're doing something that's causing this. They're something to blame for this to be happening. So I don't have to feel guilty or concerned.'

Mary is hopeful that if more White Christians knew about the causes of infant mortality for Black women, they would be motivated to do something about it.

Gail Sentry<sup>7</sup> shares Mary's sentiment that the public is grossly uninformed about infant mortality in Milwaukee. Gail is a White woman in her sixties and has worked for the Milwaukee Health Department for seventeen years. She holds two master's degrees (one in social work), and works intimately with the Fetal Infant Mortality Report. As part of her role with FIMR, she gathers information from the birth and death certificates of infants who die, and reviews the medical charts of women and their babies. She uses statistical analysis to show the entwined relationships between risk factors for infant death and the particular socioeconomic and racial/ethnic makeup of Milwaukee. She also conducts some of the interviews with parents who have experienced stillbirth or infant death. These experiences have endowed Gail with a deep sense that what we are doing to combat infant mortality and the disparities therein are not enough.

Gail is critical of the way infant mortality is portrayed by the news. When we began to speak about the public perception of the cause of infant mortality, she stated, "If you watch the news, its safe sleep. You know, and that's all it is." Gail sees newscasters laying blame at the feet of the parents for not practicing safe sleep, which translates to a misplaced blaming of parents for the majority of infant deaths by an uninformed public. When I asked Gail about the Black-White

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<sup>7</sup>Gail Sentry [pseudonym chosen by collaborator], interviewed by author, Milwaukee, WI, June 16, 2017.

disparity in infant mortality, she remarks, “it’s held up for ages,” and expressed frustration that the racial disparity gap between Black and White infants is widening.

For Gail, there seems to be more than just public misunderstanding. She points to a problem of apathy for the plight of Black infants. Gail gave me a telling example of how racial bias shapes the way the public, including health care professionals, view this gap. She references a graph that shows the infant mortality rate by race/ethnicity. The infant mortality rate is on the y-axis and time, measured in years, is on the x-axis. Then there are multiple lines representing different racial/ethnic groups: the one representing Black infants highest on the graph, and the lines representing White infants and also Hispanic infants are the lowest. She said, “If we were to show that rolling averages graph with Whites on the top, everybody would be, you know, down our throats saying ‘Why are you letting all these babies die?’” Gail’s point in presenting this thought experiment is to highlight her perception that while Black babies dying three times more often than White infants appears not to cause an outcry, she believes that if these data were flipped and we were to state that White infants die three times more often than Black infants, the public would be horrified.

Gail goes on to describe how her colleague has actually conducted this exercise with groups of professionals and students, for the “shock value.” She continues, “People have pointed out to him ‘No, you’re wrong. This is a wrong graph. You did this wrong.’ And he says, ‘Why, what’s wrong with it?’” She laughs, not because the situation is humorous but because of the discord it presents. This exercise points out the uncomfortable incongruence of recognizing within oneself different responses to a 3:1 Black to White IMR ratio versus a 3:1 White to Black IMR ratio. By asking the question “What’s wrong with it?” her colleague presses this point,

hoping those who called the graph “wrong” would not see it “righted” by simply switching back the labels “Black” and “White.” Indeed, the graph represents a moral wrong even when it correctly represents the reality.

What can we learn from this anecdote: that, when presented with a Black IMR of 15 and a White IMR of 5, students and professionals don’t bat an eye, but when the tables are turned, everyone is up in arms? First, it points to an underlying understanding among the public that such a high Black IMR is not only not shocking, but taken to be normal. In a way, it confirms that Milwaukeeans know that Black babies die much more often than White babies. They may not know exact figures, but there is a tacit understanding that this graph represents a reality that does not warrant outrage. Second, the outcry experienced when Gail’s colleague flips the labels “Black” and “White” is telling in its own way. It points to a perception that White infants could not possibly be dying more often than Black infants, and also that that high of an IMR for White infants is unacceptable. While seemingly simplistic, this perception makes tangible a difference between how the public views groups of infants—and implicitly their mothers and families as well—based solely on race. The next section takes a deeper look at how racial differences negatively affect Black women, infants, and families in Milwaukee.

### **“Society Makes Black People Look So Bad”: Barriers to Health for Black Women, Infants, and Families**

I met Sister Faye and Missy<sup>8</sup> one afternoon at the cafeteria of the Catholic hospital that is a sponsoring partner of the Strong Baby Sanctuary program. I knew Missy and Sister Faye from

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<sup>8</sup>Sister Faye and Missy [real names, identification chosen by collaborators], interviewed by author, Milwaukee, WI, September 5, 2017.



previous Strong Baby Sanctuary events, given that we hold in common the role of Strong Baby Sanctuary group leader at our home churches. Sister Faye and Missy both describe themselves as Black or African American and are from the same African Methodist Episcopal church, which is one of the most longstanding African American congregations in Milwaukee. Sister Faye, whose husband is the pastor, started the Strong Baby Sanctuary at their church, and had recently recruited Missy, a church member, Strong Baby Sanctuary group participant, and mother of two children, as a co-leader. Missy's infant (who is also Sister Faye's godchild) was also with us that day, and Missy was just finishing up a breastfeeding session as I began recording.

Near the beginning of our conversation, I asked Missy and Sister Faye what motivates them to lead a Strong Baby Sanctuary program at their church. Sister Faye replied, "I have always been a caretaker," and described how her passion for this work stems from her background in home health care for the elderly and in caring for children. Missy simply stated "I just like helping people." She discussed her excitement to help educate fellow mothers and help them get support, saying "I think all mothers need help somewhere." Then Sister Faye shared that when they first learned about the Strong Baby Sanctuary program, three babies had just died in their community. Missy talked about a young woman she was working with whose older baby rolled on top of an infant which resulted in the infant's death. Later, Missy also shared that her sister just lost a baby through stillbirth. While Sister Faye relayed that she did not personally know the families of the infants who had died, she lamented "It's always hard to hear that a baby passed away. So any help that we can do as a church to relieve the stress for the mother or to help make sure that they know that there's programs out there for them that can help them."

Sister Faye and Missy are keenly aware of the comparatively high rates of infant mortality among Milwaukee's African American families, as well as how the risk factors for infant death manifest in individual women's lives. They both relayed concern about those risk factors that are influenced by maternal behavior. Sister Faye mentioned that a lot of women don't go to the doctor as often as they should: they might go to find out they're pregnant or for the 20-week ultrasound to find out the baby's sex, but as Sister Faye sees it,

[T]he next thing you know they don't go back until they have the baby. So in between there is no care. We don't know if they're taking their prenatal vitamins or if they're eating right or if they're under a lot of stress that maybe the church or this program can help them with.

Education on nutrition, the importance of prenatal care, and stress reduction are key components of the role Sister Faye and Missy play through their church's Strong Baby Sanctuary program.

As we continued talking, it became clear that Missy and Sister Faye struggle with negotiating the role social determinants play in women's lives as they strive to support their agency and ability to parent.

### **Medical Paternalism and Parental Agency in Safe Sleep Counseling**

As part of their role in educating families about infant care, Sister Faye and Missy are advocates for safe sleep.<sup>9</sup> Sister Faye shared that she'd never heard of safe sleep when she was raising her children, and that bed sharing is a common practice in the African American community. She described counseling one young lady, telling her "Would you rather your child

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<sup>9</sup>Discussions about infant safe sleep in the public square can be polarizing, and I want to recognize that it was difficult for me to write this section. I did not want to represent myself as someone who disregards the real risks present in some co-sleeping situations, or someone who is out of touch with the lived reality of mothers and why they and some health professionals continue to promote bed sharing as safe in specific situations as well. As a new mother myself, my own experiences and choices about our sleep habits during that first year continued to guide me into the complexities of this issue, and the reality that there are not only two positions, but a spectrum of viewpoints on infant safe sleep that take into account varying factors including baby's health and parenting practices.

be alive, or just because you're tired and don't want to get back and forth up every time she or he cries for a bottle... would you rather take that chance?" Here Sister Faye is giving an example of counseling moms on the risk factors associated with bed sharing. To some moms, this kind of talk might border on scare tactics. However, considering the militancy of how safe sleep has been embedded in health care and public health rhetoric—and accordingly, the Strong Baby Sanctuary curriculum—and because of my connection to the program, perhaps Sister Faye was presenting a harsher retelling of her story that muted the actual, perhaps more compassionate, exchange.

In either case, what is missing from this narrative is that cultures all over the world—including those in Europe and White women in the US—also practice bed sharing in ways that are inconsistent with recommendations of health professionals.<sup>10</sup> However, some groups hold bed sharing to be safe, especially for breastfeeding mothers and infants. This exchange exemplifies how an unwarranted focus on safe sleep can contort a good intent of teaching about safe sleep into a conversation that may come off to a mom as shaming and blaming them, which in turn can erode their trust in those who represent health care.<sup>11</sup>

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<sup>10</sup>Barbara Welles-Nystrom, "Co-sleeping as a Window into Swedish Culture: Considerations of Gender and Health Care," *Scandinavian Journal of Caring Sciences* 19 (2005): 354-360; Melissa Bartick et al., "Babies in Boxes and the Missing Links on Safe Sleep: Human Evolution and Cultural Revolution," *Maternal and Child Nutrition* 14, no. 2 (2018): 1-7. P. Blair and H. Ball, "The Prevalence and Characteristics Associated with Parent-Infant Bed-Sharing in England," *Archives of Disease in Childhood* 89, no. 12 (2004): 1106-1110.

<sup>11</sup>When I shared the above paragraph with Sister Faye via email, she wrote back that the last part "was harsh." She further explained that "[W]e are taught that it's important not to sleep with the babies. All cultures view it different as I stated earl[ier] about the African American community in general. We are told to reeducate on the importance of safe sleep." Given our discussion in the next paragraph, I do not believe that Sister Faye and Missy are part of the problem of blaming and shaming moms about safe sleep, and quite the opposite, I believe they help women discuss the difficulties of infant sleep and come up with solutions where they feel supported as parents. However, I do think that without careful attention, some well-intentioned people could fall into this trap of shaming and blaming while engaging in safe sleep counseling.

When I shared a personal experience with Missy and Sister Faye, it opened up a more real conversation about the struggles women have with infant sleep and why co-sleeping might be practiced. When I bemoaned having a hard time getting my five-month old to sleep in her pack n' play after bringing her into our adult bed to breastfeed, Missy shared that she's having a similar issue. She recounted how her and her fiancé practice skin-to-skin with their newborn, which is great for bonding, but makes it difficult when the baby falls asleep and they try to transfer him to his crib. Considering Missy's experience, Sister Faye then reflected upon her daughter's remarks after a Strong Baby Sanctuary luncheon where safe sleep was preached, who had said, "Well, it starts at the hospital where they want you to have that skin-to-skin."

Combining a response to both her daughter and Missy's remarks, Sister Faye empathized,

And then it's hard once you get home and you try to detach yourself from the baby to lay him down or lay her down and [s/he's] crying and then you're tired and you want to lay... It's not that we're trying to tell you what to do or how to raise your child, but we just want you to be safe.

Here I take Sister Faye's sentiment to be more representative of how she approaches safe sleep discussions; how she tries to balance her response and base it in an understanding of the lived experience of a tired mom with a newborn baby.

Sister Faye's approach to talking to moms about safe sleep in this scenario has some similarities with that of a home-visiting public health nurse. Claire Smith is White and a bachelor's degree nurse working with the Milwaukee Health Department. Claire has 11 years of experience in health care, including working as a certified nursing assistant (CNA), labor and delivery nurse, and postpartum nurse. With the Health Department, she has supported two home visiting programs. In her current role, she supports first-time mothers from pregnancy through

the child's second birthday. Claire loves building long-term relationships with families, helping them meet their goals, and seeing them "graduate" the program.

Claire gave an example from her experience of an approach to safe sleep in a way that is understanding of the mom's situation, supports parental agency, and still counsels about recommended practices:

One example I can think of recently is... first time mom, just had a baby. And [she] was just like, 'It's going so good, and I'm nursing every couple hours.' And she's like, 'I felt so bad because my mom brought my baby to the bed so I could nurse in the middle of the night and I fell asleep!' And then she's very like in the trend of like, 'No, it's bad, you can't ever co-sleep with your baby,' too. But yet—and when her mom's time too—that was a cultural thing. You would co-sleep. And then, her mom's reassuring, 'Oh no, it's okay, it's okay,' and yet the client is freaking out about it. I just kind of like reassured her, I said: 'You know what, yes you don't want to sleep with your baby, but you know sometimes accidents happen. You can't beat yourself up about it.' I said, 'Ideally this is the situation. Is this accident going to happen? Yes, you know what I mean, because you're breastfeeding. What can we do to actually, kind of maybe create that—do we need to put your pack n play or your bassinette like right next to bed? So it's not so far away? So then you just could kind of roll over and put baby in the bassinette/pack n play instead of like get up out of bed? Or like set a timer or alarm to wake up in case you do fall asleep. So just trying to create some creative solutions and different options.'

Like Sister Faye, here we see Claire taking a middle ground position. While she stands by evidence-based practices, she attempts to offer a compassionate ear to her client and then work with her to establish practices that are both safe and supportive of the mom and her situation.

Greg Johnson,<sup>12</sup> a family medicine physician and obstetrician, provided an example of how he counsels parents about infant safe sleep. Greg Johnson describes himself as an upper-middle class, middle-aged Caucasian male physician. He has been caring for patients in

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<sup>12</sup>Greg Johnson [pseudonym chosen by collaborator], interviewed by author, Milwaukee, WI, June 14, 2017.

Milwaukee's inner city for about three years, and about 80-90% of his patients are African American. He shared these thoughts:

I tell them, I try to point out the fact that for most people it's fine, but, 'If you woke up and were laying on top of your baby, how would you feel? You know, that would be awful! So that's why I'm talking about this. So that's why it's important to have your baby in their own sleeping area.' And it's a numbers game.

Greg preceded this statement with a discussion about how co-sleeping deaths are "really, really rare," "just the tip of the iceberg [of infant death]," and his knowledge that "a lot of mom groups are very pro co-sleeping." Dr. Johnson then brought up the practice of stomach sleeping that physicians endorsed when he was an infant, saying "I slept on my face every day and that's what they told everyone to do. And I lived." I did not take his statement to be flip, but instead coming from a place of medical humility, showing he is cognizant that historical recommendations of medical professionals are not set in stone. To avoid mistrust then, when we counsel patients about practices that are new to them, we have to take ownership of what the body of medicine has said in the past and the fact that it continues to improve. To put the risk of bed-sharing into perspective, he stated, "if you have 1,000 co-sleepers, only a few will have an awful consequence, but it's also a really awful consequence." This approach has the potential to allay mistrust by recognizing that parents come in with their own sources of information that should be engaged, changes in medical practices should be acknowledged, and all of the facts should be considered when trying to support patients to make safe sleep decisions.

Turning back to my discussion with Missy and Sister Faye, they voiced the most concern about what they termed "careless sleeping." They described careless sleeping as sleeping in an adult bed with a baby if you're a heavy sleeper or while you are intoxicated from alcohol or drugs. They are right to be concerned: the risks of co-sleeping are attributed to suffocation by

either bedding or the parent blocking the baby's airway, or by the parent rolling on top of the baby. These situations are more likely for a parent who is a heavy sleeper, or when drugs and alcohol are involved. Outside of these dangerous contexts, there are parent groups as well as professional societies that explain the benefits of bed-sharing for breastfed infants and promote safe ways to practice bed sharing.

Some of the recommendations that promote bed sharing are at odds with the Health Department's messaging in their safe sleep campaign. For example, in their guidelines on "The Safe Sleep Seven," The La Leche league holds that it is safe to practice bed-sharing if you and your baby meet certain criteria.<sup>13</sup> Offering a parent-centered approach, The Academy of Breastfeeding Medicine simply states: "There is currently not enough evidence to support routine recommendations against co-sleeping. Parents should be educated about risks and benefits of co-sleeping and unsafe co-sleeping practices and should be allowed to make their own informed decision."<sup>14</sup> Putting the informed decision in the hands of the parents not only respects normative tenets of medical ethics, but reflects one of Garcia's attributes of a bioethics that is cognizant of African American experiences.<sup>15</sup> Without such evidence, does it make sense to have hard and fast public health teachings on safe sleep?

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<sup>13</sup>The La Leche League holds that mothers who fit the following seven criteria can safely bed share with their infant: 1. a nonsmoker 2. sober and unimpaired 3. a breastfeeding mother and your baby is: 4. healthy and full-term 5. on his back 6. lightly dressed and you both are 7. on a safe surface. "The Safe Sleep Seven," The La Leche League, September 1, 2014, <http://breastfeedingtoday-llli.org/the-safe-sleep-seven/>

<sup>14</sup>Rosha McCoy et al., "ABM Clinical Protocol #6: Guideline on Co-Sleeping and Breastfeeding," Revision, *Breastfeeding Medicine* 3, no. 1 (March 2008): 38-43. <https://abm.memberclicks.net/assets/DOCUMENTS/PROTOCOLS/6-cosleeping-and-breastfeeding-protocol-english.pdf>

<sup>15</sup>Garcia, "Revisiting African American Perspectives," 3.

Indeed, some professionals point out the damage done to patient-clinician relationships when a hard stance is taken on safe sleep. James McKenna of the University of Notre Dame Mother-Baby Behavioral Sleep Laboratory states “[s]weeping public health recommendations must resonate emotionally and socially with the constituencies for whom they are intended; simplistic anti-co-sleeping messages do not.”<sup>16</sup> McKenna’s remarks critique the rigid ABCS message delivered by the Health Department. As an alternative, McKenna recommends supporting parents, not institutional bodies, as the ultimate moral decision makers for infants:

For moral, political and ethical reasons PARENTS (and not medical authorities) must remain the final arbiters of their infant’s nighttime needs and sleeping arrangements. It is an intrinsic civil right of the parent to decide where their baby will sleep. Where and when it is implied that it is not the parent’s right, the overreach must be challenged at every level, by moral, legal, scientific, and political communities and their constituencies.<sup>17</sup>

Here McKenna posits not only is it morally irresponsible for health professionals (whether from institutional medicine or governmental health departments) to make blanket recommendations when the evidence is not there; further, these public health messages forward a paternalistic and authoritarian approach that usurps the parent’s moral duty to their child.

Attention needs to be called to the moral role of the parent as decision maker for their child’s safety and well-being. This role is decidedly downplayed within the paradigm set up by ABCS safe sleep campaigns supported by clinics, hospitals, and the Health Department. In this messaging, the authority knows best, and the parent needs to behave accordingly. Further,

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<sup>16</sup>McKenna holds a doctor of philosophy in biological anthropology and is an expert on mother-infant cosleeping in relationship to breastfeeding and SIDS. James McKenna, “What Every Health Professional Should Know,” Mother-Baby Behavioral Sleep Laboratory, University of Notre Dame, <http://cosleeping.nd.edu/what-every-health-professional-should-know/> (accessed July 24, 2018).

<sup>17</sup>Ibid., emphasis original.



without a causative relationship between bed sharing and infant death, the simplistic message of the ABCS does a disservice to supporting parental agency and developing trust between parents and medical and governmental bodies.

There is an alternative message about safe sleep, grounded in evidence and supportive of parents as ultimate moral decision maker, that could easily be communicated instead. Bed sharing for formula-fed babies, or for a breastfed baby in the presence of excessive bedding, an unsafe surface such as an air mattress or couch, a partner who is a heavy sleeper, or after drinking alcohol or taking drugs has been shown to increase risks for SIDS and accidental suffocation.<sup>18</sup> Spreading this message would be grounded in research and would therefore be a more responsible retelling of the facts, which has the potential to build trust and dive into real conversations. In any case, there needs to be a broader conversation between health professionals and mothers than teaching the ABCS: at its best, a message detached from the emotional and social components of bed sharing, and at its worst, a non-evidence-based practice used to judge and blame parents—mothers in particular.

Another key component of this conversation is that safe sleep rhetoric can be especially detrimental to African American mothers and their infants. Consider at least two reasons. First, given the track record of institutionalized medicine as a perpetrator of injustices against Black bodies, there is already good reason for Black mothers to be skeptical of professionals' recommendations. If the medical community is going to recommend a safe sleep practice, it

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<sup>18</sup>Helen L Ball and Lane E Volpe, "Sudden Infant Death Syndrome (SIDS) Risk Reduction and Infant Sleep Location—Moving the Discussion Forward," *Social Science and Medicine* 79 (February 2013): 84-9; B. D. Gessner and T. J. Porter, "Bed Sharing With Unimpaired Parents is Not an Important Risk for Sudden Infant Death Syndrome," *Pediatrics* 117 (2006): 990-991; J. J. McKenna and T. McDade, "Why Babies Should Never Sleep Alone: A Review of the Co-Sleeping Controversy in Relation to SIDS, Bed Sharing and Breastfeeding," *Pediatric Respiratory Review* 6, no. 2 (2005): 134-152.

should be grounded in evidence, realistic about the risks and benefits, and supportive of parental moral judgement. To that point, a second reason current safe sleep teaching is inadequate especially for Black mothers is because of the ease with which it can be co-opted to perpetuate stereotypes of Black women. Consider how public moral imagination is conditioned by false tropes including the “strong Black woman” and the “welfare queen.”<sup>19</sup> A key feature of these caricatures includes being an unfit mother. While any mother who decides to bed share with her infant may face criticism from health professionals or other groups, Black women may face harsher condemnation given the persistence of these stereotypes in the American mindset.

### **Racial Bias in Health Care and Social Services**

Biases faced by Black mothers are not limited to their decisions about infant sleep. As our conversation went on, Sister Faye described the hardships faced by the women in her community:

In the Black community we have mothers that are working two jobs, trying to go to school, come home. They’re single mothers. They’re not getting no outside help with, ‘I’ll watch your kid,’ other than with kids being at school or daycare. And then they’ve got to come home and then she’s pregnant, she’s stressed. And that puts a lot of stress on the baby, which might cause prematurity and stuff like that. So I think a lot of people in our community need the outside help for the mothers. Because when you’re trying to go to school and you’re trying to work two jobs and you’ve got kids, we never want to demonize them because they have children, but we just want to be a help to them.

Here Sister Faye gives an example of a mom “doing all the right things”—going to school, working two jobs, and taking care of her children. She’s also pregnant, and has that added stress of caring for herself in a way that acknowledges how her health is related to baby’s health. Many parents would agree that this is a lot to juggle. Sister Faye then acknowledges how stereotypes

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<sup>19</sup>These stereotypes are discussed in Chapter Two. Williams, *Seeing a Colorblind Future*, 57; Douglas, *Sexuality and the Black Church*, 53.

unfairly “demonize” Black mothers: that for mothers who have to balance so many competing goods, and for Black mothers in particular, giving attention to anything outside of their children is considered neglectful behavior. When I asked Missy whether there is something about being a Black woman in America that is just bad for your health, she responded, “Right, because society makes Black people look so bad.” The feeling that *de facto* by living in American society you’ll be demonized and treated “less than” carries through both Missy and Sister Faye’s experiences with social agencies and health care institutions.

The theme of feeling disrespected by social service agencies and health care institutions identified by the collaborators to this project introduced in the last chapter was echoed during my conversation with Missy and Sister Faye. When I asked them about ways they feel racism, Sister Faye offered up, “Well, the W2 office always makes you feel bad.” She is referring to Wisconsin Works, a public assistance program that allocates state dollars to working parents. Missy agreed, and went further, stating, “They make you feel less of a human being.” Sister Faye then included the Women, Infants, and Children (WIC) clinic, another public assistance program that disburses food stamps to pregnant women and mothers of young children and counsels them about nutrition. She added, “The WIC office makes you feel bad. Any time you go to sign up for W2 or WIC and you are in there four to five hours. That’s degrading you, like you ain’t got nothing else better to do.” Missy agreed, and began talking about all of the other things she could be doing with five hours of her time (job searching, for instance) instead of sitting in the row of plastic chairs waiting for her number to be called. These experiences of disrespect and frustration due to bureaucratic processes resonate with Victoria’s experience with the social service agency and when asking for directions at the hospital, shared in Chapter Three. While Victoria wasn’t

responding specifically to a question about racism, she was commenting on barriers to health in her community, which seems to go hand-in-hand in Missy and Sister Faye's accounts.

Missy also likened her experiences of feeling less of a human at the WIC clinic and W2 offices to her interaction with her postpartum nurse. She said, "If I feel like a nurse is 'dink-a-dink-dink,' she's going to get replaced. I don't want nobody around me with a negative energy. Leave." Missy's use of that particular phrase carried the meaning of someone 'dinking around,' or not fully invested in the task at hand—in her case, caring for her and her baby.

I asked Missy how she could tell when a nurse has a negative energy and whether it was obvious, and she responded:

Some of them are very obvious. Like my baby, he was born at 36 weeks and two days. So he had to stay in the NICU for about a week. I had a nurse up in there. And I was like, well, 'My son is coming home.' I was like, 'I bet you by Wednesday he comes home.' [The nurse said] 'Well, I wouldn't think that way if I was you because he could be in here longer.' The next day she went in there. Do not assign her to my baby, do not have her come in here with my baby. We will take another nurse. Because I don't like her attitude, I don't like her characteristics, and I don't like how she cares for her patients.

In this experience, Missy attributes the nurse's hesitancy to be on board with Missy's optimistic plan of bringing her son home to "negative energy." I wonder if there might be another factor underlying the nurse's view. There is a danger of succumbing to a sense of hubris for health care professionals. Hubris can be understood as a sense of arrogance about the expertise of science and medicine while ignoring harms caused by evidence-based practices throughout history as well as the realities of present-day unknowns.<sup>20</sup> While some physicians and nurses are better at keeping it at bay than others, hubris seems to flood in during situations that are ripe with

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<sup>20</sup>Stephen J. Genuis, "Diagnosis: Contemporary Medical Hubris; Rx: A Tincture of Humility," *Journal of Evaluation in Clinical Practice* 12, no. 1 (2006): 24-30; B.M. Hegde, "From Hubris to Humility," *The British Medical Journal* 351 (July 2015), <https://www.bmj.com/content/351/bmj.h3857/rr-0>

unconscious bias. It is difficult to know from Missy's limited description the nurse's intentions behind her remarks. At best, she was trying to give Missy realistic expectations, but at worst the air of a paternalistic "nurse knows best" may have been at play, and a hubristic judgement that Missy's desire for her son to go home was not based on what was best for him.

When hubris is present, it does not bode well for building trusting relationships between patients, parents, and health care professionals. It also plays into the stereotype of "mothers behaving badly" that is disproportionately placed upon Black women. If the nurse "knows best" and Missy has a different plan for her newborn in mind, Missy might be perceived as behaving as a neglectful mother.

Missy continued her story by linking her experience to stress: "Because sometimes that's where a lot of stress comes from. You go to the hospital because you're having contractions and they tell you, 'Oh, ain't nothing wrong with you.' You don't know what's wrong with me." In this example, medical hubris is at play in a different way—a way that challenged Missy's knowledge as a woman based on her own bodily experience. Not only does this example link the medical community's complicity in injustices against Black bodies to mistrust, but also to the toxic stress that is so harmful to Black women and their babies.

Sister Faye shared a similar experience that shows the complex interplay between bias, race, and insurance status. She told an emotional story about her nephew who struggled with the symptoms of sickle cell anemia throughout his life until he died at age 27. Reflecting on the times she and her husband took their nephew to the Emergency Department during a pain crisis, she said:

He would sit there in that waiting room in excruciating, excruciating pain. Excruciating pain. I can say that maybe it was because he was Black, maybe it was because of the

insurance. But a lot of times when you have [Medicaid], and the majority of them are Black, they treat you that way.

While we don't know whether Sister Faye's nephew was made to wait longer than necessary on that particular evening, we do know that studies show that health care professionals in general are less apt to adequately diagnose and treat pain in Black patients when compared to their White counterparts.<sup>21</sup> A more subtle but nonetheless poignant issue raised by this experience is the effect of internalizing the unsettling feeling that your race or your insurance status might be a contributing factor in you or your loved ones receiving substandard care. While it violates federal law to discriminate based on insurance, and in an Emergency Department everyone has the right to an assessment and stabilization before being asked about their insurance status, these regulations cannot police how bias based on race or insurance status plays into pain assessment or wait times.

Sister Faye is not alone—one study shows that of one hundred patients insured by Medicaid who frequent the Emergency Department, a common experience was negative personal experiences with the health care system.<sup>22</sup> Another study shows that when bias is at play, Black patients can experience longer visits, their clinician using slower speech, and overall they rate their interpersonal care encounters lower.<sup>23</sup>

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<sup>21</sup>Kelly M Hoffman et al., "Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs about Biological Differences between Blacks and Whites," *Proceedings of the National Academy of Sciences of the United States of America* 113, no. 16 (2016): 4296-4301, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4843483/>

<sup>22</sup>Roberta Capp et al., "Reasons for Frequent Emergency Department Use by Medicaid Enrollees: A Qualitative Study," *Academic Emergency Medicine* 23, no. 4 (2016): 476-481.

<sup>23</sup>Lisa A. Cooper et al., "The Associations of Clinicians' Implicit Attitudes about Race with Medical Visit Communication and Patient Ratings of Interpersonal Care," *American Journal of Public Health* 102, no. 5 (2012): 979-987.

Sister Faye described how she negotiates finding a health care provider that will treat her with respect. She said she hasn't really dealt with racism in her personal interactions with health care professionals, and attributes this to her proactive research into finding out "what type" of provider, clinic, and hospital she will visit. She then shared, "I'm not going to say I'm going to get the best hospital or the best doctors, but I'm going to get somebody that's attentive to what I need." Putting in the effort to finding a doctor that's attentive to her needs is a clear expression of Sister Faye advocating for herself. However, she qualifies that this prioritization of attention to her needs could come at the cost of not getting "the best" care. By making this statement during our discussion of how race and insurance bias factor into health care, it appears that those who face these biases may be forced to consider trade-offs in trying to find respectful *and* quality health care that those of other races and insurance statuses do not.

### **The Distorting Perception of White Privilege**

Katy Lubner, who describes herself as a White middle class female in her thirties, has a master's degree in social work and runs the dad's program at the Milwaukee Health Department. Katy shared with me her perspective on the interplay between how racism shapes the daily lives of Milwaukeeans and the collective responsibility of White people to respond. When I asked her whether she thought people treat others differently based on skin color, she said:

I think so. I mean, I absolutely think so. We hear that from clients. We hear stories about when they're accessing medical care, the way they're treated when they call for an appointment or show up for an appointment. I think that there's also this lack of understanding of what the impact that being in poverty has on a family. I think that race is really important and I think that it's the reason... I'm trying to think how to say this. I think a White family in poverty is treated differently than a Black family in poverty. I think we see for example a family that's Black, and the mom is late to her appointment because she had to get all her kids on the bus, and that's really hard to do, and the clinic is like, 'Eh, you're fired. You're not gonna be our client anymore.' No empathy or trying to understand what it's like to be in poverty and not have your own car and not have your

own space to live, and not have a babysitter—not be able to pay a babysitter to watch your other kids. I think that if it were a White family coming in with that, I think a lot of times they would have more empathy or they could get a second chance. Whereas I think that being Black *and* being in poverty is like, a lot of clinics or a lot of professionals just write them off. Or just don't give them another chance; don't even try to understand what's going on. I think the stress of that—there's been a lot of research around what stress does to your body, what elevated cortisol levels do both to a fetus, but also contributing to preterm labor, and so I do think that that is playing a huge role.

As a home visiting social worker who works to build up trusting relationships over time, Katy has been able to learn from her clients about the kinds of everyday racism they experience. She shared that she learned how people of color have to always be “on guard” because “they never quite know what kind of interaction they’re going to have” whether at prenatal appointments, shopping, or when driving by a police car.

Katy's experiences mirror what is found in the literature and provide an outsider's perspective on similar experiences shared by some of the collaborators in this work. Her insight about the intersection of poverty and race reflects the discussion in Chapter One of this work, where studies were introduced that show while poverty is tied to poor birth outcomes for women of all races, it comes to be most devastating for poor Black women and infants.<sup>24</sup> Katy's highlighting of her clients' shared experiences of being treated without understanding and empathy are key, and are reflective of stories shared by my research collaborators Victoria and Missy. She recognizes that these situations are stressful, and is aware of the negative physiological effects of pervasive stress on pregnant women. For Katy, putting these pieces together presents a complex picture of socioeconomic and racial barriers to health for Black families wherein White people have a responsibility to push back against the *status quo*.

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<sup>24</sup>See Chapter One, pages 12-19.



Katy then shared with me her perspective on our collective responsibility as White people to take steps toward racial justice. She said, “As a White person it’s on us to really do the work.” She described how she sought out a course called Unlearning Racism, a multi-part class that covers the history of African Americans in this country and Milwaukee “and everything that played into the inequality that exists now and why we are still here.” Kathy shared how this course allowed her to have “some of those really hard conversations with someone of a different race.” Many of Katy’s co-workers have gone through the same training, and she would love to see medical professionals go through it as well, although she thinks “everyone’s going to say they don’t have enough time.” As I thought about all of the continuing education medical professionals are required to go through, I commented to Katy that it’s not just an issue of time, but of prioritization, and she agreed.

Katy thinks it would help White people to understand how race affects people of color by “having a more integrated day-to-day life,” but balances that with being “careful to not put the responsibility on people of color to educate us.” When I asked Katy whether White people need to talk to each other more about what it means to be White, she said:

Oh, absolutely. Yes, I see it as my job to talk about--to people, especially about what my experience is. I think that I’ve been in a unique situation with being a social worker and working in Milwaukee and having the opportunity to work with families that are so different than mine. And I find myself all the time sharing little stories or my experiences. Or like I’m in a book club with a bunch of my friends, we’re all White, every month. When it’s my turn to pick, I pick a book that’s about racial justice or something. And it’s little things that I can do. But I absolutely see it as my job to start those conversations and push people out of their comfort zone.

Katy’s conviction that White people have an important role to play in discussing Whiteness and privilege reflects Jennifer Harvey’s approach to the responsibility of White Christians in seeking

racial reconciliation introduced in Chapter Two.<sup>25</sup> Perhaps putting repair and repentance into practice for White health care professionals should include taking classes like *Unlearning Racism* and having hard conversations with their White peers that are decidedly outside of their own comfort zones.

When I asked Katy how she engages her White friends or colleagues in discussions about their privilege in real time, she said, “If I hear them say something that kind of makes me think, that was racist, or that was a little iffy, I do a lot of sharing of my experience.” She continued, “I don’t think it works to say ‘Wow, you’re racist.’ Even if that’s what I wanna say. Or even if it’s true. That doesn’t make people want to change.” Instead, she tries this approach: “My life experience is different than yours; let me share it with you.” Katy shared with me that both her experiences working with African American and Latina/o families and as a White woman married to a Black man and raising a biracial child have informed her insights on White privilege.

### **Lack of Support for Dads**

Another theme with important implications for Black families that came out of these conversations was the way Black fathers are seen and supported—or, often times, disparaged and ignored. Katy revealed how often dads are overlooked and forgotten during pregnancy, birth, and infant care:

I definitely think they’re left out. I think, you know, we hear that from dads a lot, saying that where as they see their partner being embraced, fawned over, and the center of attention, they’re not getting that. So, you know, they specifically talk about feeling really left out at a prenatal appointment that they attend, that most of the time they’re saying you know that the doctor doesn’t even acknowledge me, certainly doesn’t ask me—or you know, if she says “Hi” they’re not asking me like, do I have any questions,

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<sup>25</sup>See Chapter Two, pages 73-77.

do I have any concerns. So we're there saying, 'You should go to these appointments with your partner, it's really important,' and they're saying, 'Why, the doctor doesn't care if I'm there, and sometimes I feel unwelcomed, you know, going above and beyond just ignoring me, I feel like they don't want me there.'

This perception that dads and dads-to-be are not important social support persons for pregnant women, mothers, and infants is unfounded, as will be discussed momentarily.

First, it is important to recognize that this stereotyping of fathers can also occur in medical settings.

One part of the reason dads are feeling left out specifically during prenatal appointments is because of domestic violence screening, an important part of prenatal care aimed at protecting the pregnant woman's safety. Katy continues:

Like I know some clinics, and I understand why they do this, but they'll say if a woman comes with a man they'll take the woman back first, alone, so that they can ask her about domestic violence. Which, I understand why they're doing that. But I think the message that sends to men is like, you know, we think you're perpetrating domestic violence. So I don't know what the answer is, but I know I've been to clinics, I know Clinic A does that. And I think that's a great clinic, I really do, and I would try to get a lot of my clients into that clinic. And again I understand why they're doing it, and I don't know what the answer is exactly, I think domestic violence screening is important during pregnancy and it's hard to do if there's a partner in the room. But I think that, you know, dads kind of see that as, wait a second, I don't feel welcome here if that's what you think about me.

While agreeing that domestic violence screening is important, at the same time Katy is dissatisfied with the way it alienates fathers from the prenatal care experience. This is an example of what she mentions above—not only do the dads she's worked with feel more like a piece of furniture than a parent-to-be during prenatal visits, but sometimes they feel that they are treading on foreign territory that is hostile and set against them from the get go. While Katy repeats that she doesn't know what the answer is, she implies that there must be a better way to both welcome fathers as important partners in prenatal care and effectively screen for domestic

violence. She sees this barrier as perpetuating the myth that dads are not an important part of childrearing, and her goal is to have dads be recognized as “more than a paycheck” for the nurturers and support system they truly are for an infant and mother.

Those looking to support Black fatherhood involvement in Milwaukee would do well to understand how stereotypes of Black men are at play in the minds of the public. Similar to the tropes of Black women discussed earlier, the dehumanizing myth of the “violent buck” is alive and well. This stereotype concocts the image of a Black man as physically dominant, motivated by sexual conquest through brutishness and rape, and is devoid of any character traits of a nurturing parent.<sup>26</sup> While being asked to leave the room during a domestic violence screening may be uncomfortable for any male partner, for Black men, it could be seen as a confirmation that their health care professional subscribes to this stereotype. While it is incredibly important to screen for domestic violence, there may be better ways to both ask the necessary questions and engage in respectful behavior towards the father-to-be.

Black men are also affected by another stereotype common to men in general: that the role of fathers is as financial breadwinner, not of caretaker. For example, I had the opportunity to present some of my dissertation research to a group of pediatric resident physicians. After my presentation, I stayed to hear the next presenter, a social worker who happened to be part of Katy’s dad’s program. The residents were surprised to hear that the majority of Black fathers that social worker worked with are involved in their child’s life through the age of 18 months.<sup>27</sup> The belief of this social worker, a Black father himself, on why fatherhood involvement fell off

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<sup>26</sup>Douglas, *Sexuality and the Black Church*, 45-50.

<sup>27</sup>This social worker shared with me that this data has not been published in a formal study, but was part of an internal project conducted in his department.

around that age was tied to this wider stereotype that both moms and dads do not see an active role for fatherhood that is not based around financial support. The thought is that when the intense hands-on care infants need begins to slow as they gain independence, it becomes more manageable for one person to meet the physical needs of the baby. At this point, the role mom and dad play are renegotiated, and gender stereotypes factor in heavily. The effect of this stereotype on men who are temporarily unemployed or stuck in a cycle of poverty is a message that without a paycheck, they are not a worthy parent. In his role, this social worker met with groups of Black fathers to start discussions that pushed back against this narrative and reclaim legitimate roles of nurturer, caretaker, and teacher for fathers. One of the pediatric residents shared that he was surprised by the statistics, and will think again about how he interacts with fathers during their children's doctor appointments. What this exchange showed me is the importance of discussing these issues with health care professionals, who have the power to either reinforce or push back against how these stereotypes shape the lives of Black families and infants.

### **Trust and Mistrust in Family Planning**

Reproductive life planning was a common theme among the collaborators to this project. Many of the professionals I spoke with underscored the hesitancy with which their patients and clients engaged with them in discussions about birth control, especially IUDs and hormonal methods including the pill. The collaborators to this project picked up on some of the mixed messages that might underlie this hesitancy: for example, while IUDs can be safe and effective, some women do have pain, bleeding, and other side effects—and these, instead of the successes, may be the stories women pass on to their friends and relatives. These mixed messages come

from a variety of competing social sources—health care professionals, churches, health policy, friends, family members—that can have varying degrees of influence in women’s lives. Health professionals have to figure out a way to both honor the experiences their patients bring with them into the clinic, and respectfully push back against myths that are medically unfounded.

Many of the collaborators to this project who are also health professionals spoke about the inadequacy of family planning education and resources for Milwaukee families. Luke Wilson is a family medicine physician who has just finished residency and taken a joint clinical and faculty member position at the clinic affiliated with the Catholic health system that is partnered with the Strong Baby Sanctuary program. This is the same clinic where Greg Johnson works, and Luke also sees primarily African American patients. Luke and I had met previously at the Catholic hospital while he was on an internal medicine rotation and I was completing a master’s fellowship in ethics. Luke is 29 years old and identifies as Caucasian, Christian and upper-middle class.

As we were talking about family planning, Luke brought up his perception that there is a lot of hesitancy among his patients concerning birth control:

I’ve kind of noticed that in general there’s a lot of word of mouth in terms of birth control in our patient population here. It’s more of like, ‘My friend said this, my mom told me this, I had a cousin that told me that,’ so there’s a lot of hesitancy to birth control in that regard because they’ve heard horror stories and that’s their only reference point for birth control. They don’t hear, ‘Oh this IUD worked for so many people.’ They only hear the one time it didn’t work or there was a complication.

Sharing experiences about their contraceptive experiences with friends and family is certainly not unique to African American women. However, the particular history of reproductive medicine and women of color certainly sets a different stage than for White women.

He continued by reflecting on why he thinks this hesitancy might be so prominent among his patients:

There are certain—not that all of our patients have a distrust—but I think a lot of women in our patient population, they want to have, like, not—what’s the right word—I think they like having control over their body. and there’s a certain amount of, I wouldn’t say distrust in the medical field, but just kind of a sense of questioning in terms of all medical professionals in things that they don’t disagree in terms of what we say when it comes to birth control, because again, it goes back to do they believe more of their family, friends than what they hear a doctor saying, ‘IUDs are very effective, blah blah blah blah. They’re more prone to question that rather than say, ‘Okay.’

Here, Luke picks up on the visceral connection between birth control, bodily agency, and an underlying sense of mistrust of medicine. While Luke is hesitant to label birth control hesitancy as mistrust, there may be good reason for doing so. Given the history of medical institutions sterilizing women without their consent—including a disproportionate amount of women of color—we might do better to consider that women are justifiably distrustful during family planning conversations with health care professionals.<sup>28</sup> Acknowledging that mistrust of medicine is not a character flaw in a patient but a symptom of a greater social injustice that medicine has been complicit in opens up a different conversation about how to build trust. Instead of focusing only on education as a means to build trust—which assumes if women only knew what health care professionals knew about birth control, they would choose to use it—we would then need to better consider building trust through shared goals and partnering with women to meet their needs.

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<sup>28</sup>See discussion and references in Chapter Two regarding the complicity of the medical profession in sterilizations without the informed consent of women of color.

Luke shared some additional thoughts about family planning hesitancy that might be fruitful for different ways of building trust with women of color. He mentions both supporting women's control over their bodies and their desire to seek counsel from trusted loved ones:

I think there's that initial, not only sense of wanting to have control over their body but to make sure that they're counseling with their family before they actually make the decision, if that makes sense. I can't even count how many patients that say, 'I don't want any hormones in body.' Like they think it's something like, we're almost controlling that. And I think it's a control thing for a lot of patients.

Consider how a family planning conversation centered on a patient's agency and control over her body, coupled with encouraging her to seek counsel from her family, might look when compared to one that is heavy with a recommendation for choosing a form of birth control today.

Like Luke, Claire is passionate about making sure patients know all of their options when it comes to family planning. For her part, Claire is sure to point out that not all of these options include hormones or medicine at all. Claire segued into a discussion about birth control when talking about her clients who get pregnant again during the two year follow up period:

[Birth control is] viewed, depending on where you go, good and bad. And it doesn't necessarily have to be a bad thing. I think the point is—and our goal is—mostly to educate women about their options. And I get it—when you're in school, there's a push for maybe no birth control, no nothing, no sex ed, and then you have religious groups who are like, 'No, no, no, abstinence, abstinence, abstinence,' or you have cultures like, 'No you can't use hormones,' or things like that. And being a provider, nurse, social worker, whatever, that is there to educate—our job isn't to tell you what birth control to take and that you should be on it. Our job is to educate you so you know the options of everything that is out there. (24:30)

Consider Claire's perspective from the vantage point of building trust. If women are justifiably skeptical that a health care professional has a hidden agenda when it comes to birth control, one way to overcome that might be to ensure all options are presented, including natural methods and abstinence. Presenting information in this way could be another strategy to help build trust.



### **Mixed Messages from Churches**

Claire also brought up her own hesitancy when it comes to the messages churches spread about sex education and family planning options. When I asked Claire what message she would give to church support group members and church leaders, she said:

I would say to the pastors, the first thing that comes to my mind is birth control. I would say, be open to the education of it. Allow people to be educated about it. Just 'cause they're educated doesn't mean they're gonna go for it but at least they can be educated... It's not a stance for or against it but at least you're being educated about what's really going on in the world and options. I think everyone thinks birth control—it's a hormone, it's a hormone—no! We talk about things like natural family method, like rhythm mucous method, basal body temperature, cycle bleeds, those are non-hormonal methods. Abstinence... It's not all just medication and taking a hormone.

Here Claire makes two points to consider. On one hand, she's reminding faith leaders that not all forms of family planning are contrary to church teaching. However, given that those churches with dogmatic guidance on birth control also hold marriage as the proper relationship within which to practice family planning, this argument may not be satisfying to some clergy when it comes to unmarried persons. Claire's second point is that separate from church teaching, women ought to know all of their options, and supporting holistic education on family planning options need not constitute an embrace of certain practices. Again, this argument may not hold weight for some church leaders. However, given that the mission of the Strong Baby Sanctuary is open to not just church members but women of varying faith backgrounds within the community, perhaps church leaders who are apprehensive about family planning education within their walls to think again about the arguments Claire makes here.

Some churches may see Claire's concern as a non-issue. When I asked Missy and Sister Faye how their pastor (who, I learned during our conversation, is Sister Faye's husband)

approaches issues like birth control and sex before marriage, Missy said, “He still encourages marriage, but he’s not going to judge you.” Sister Faye agreed, saying “He doesn’t judge. He’s open.” She continued:

[In] a lot of churches you see the young folks are running from the church. And a lot of the reasons are because of the judgements. Or, ‘I’ve been told that I shouldn’t drink, I’m going to go to hell.’ Like that. And [our pastor says], ‘Do they say that in the bible?’

I commented that some people probably hear that God says you should never have sex before you’re married, and Sister Faye replied,

That’s not in the bible. But what [pastor] does say is this: and he uses Mary Magdalene where they were stoning her... and he told them in so many words that ‘Let the first one that has not sinned cast the first stone. We all sin and fall short of God’s glory.

Some might see this perspective as a refreshing turn away from a focus on sexual immorality and back to Scripture, focusing on the gospel message teaching us not to judge. However, sex can also be interpreted in this context to be sinful for unmarried women—a sin we shouldn’t judge, but a sin nonetheless. Pastors and church leaders who support Strong Baby Sanctuary programs need to think critically about how their messages come across to women in their groups who are not church members, were raised with different interpretations of Scripture, or have different moral values when it comes to sexuality, marriage, and family planning.

Despite the noted room for building understanding and trust around family planning for both women of color and health care professionals, this issue may not be central to confronting infant mortality. Given the frequency with which the collaborators to this project brought up family planning, it’s worthwhile to consider that there may be an underlying mindset that if unplanned pregnancies were eliminated, we would not be facing an infant mortality crisis. There is some data to support that Black women do experience unplanned pregnancy more frequently

than their White counterparts.<sup>29</sup> However, other factors like educational attainment and financial security also factor in, unplanned pregnancy being more often experienced by lower-educated women and women who live below the poverty line. Given the unequal power dynamics of race and class between some cohorts of female patients and their health care professionals, perhaps supporting female reproductive agency frames a more responsible approach to this issue than working to eliminate unplanned pregnancy.

While not related to family planning, Gail Sentry also shared with me another type of negative experience with faith communities around issues touching infant mortality. While I did not directly ask Gail about her religious affiliation, at one point in our conversation, she expressed that she has had negative experiences with religion. She takes a tentative stance, then, when considering the contributions faith-based programs can make to lessening infant mortality in Milwaukee. For example, she is critical of the insensitive ways many pastors and others from faith-based communities have treated mothers and families who have lost a baby. She shared:

I don't worry usually about anything they have to say in terms of the medical piece. I worry more about the bereavement piece. When families have a loss, I think there are right things to say and wrong things to say. Saying, 'You can do it again, no problem,' or, um, 'Rely on your faith,' [sighs]... So I just think there are things that I've heard from a lot of faith-based places that I have issues with. And you can't—I don't have the words to turn them around. If I had the ability to make them understand how they're harming people with what they're saying, then that would be better. But I don't know how to do that.

Later Gail commented, "I suspect *they* think they're being sensitive," meaning that church leaders' good intentions can still come across as deeply hurtful when not informed by practices developed by experienced grief counselors. Given the frequency with which Gail has

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<sup>29</sup>"Unintended Pregnancy in the United States," Guttmacher Institute, <https://www.guttmacher.org/fact-sheet/unintended-pregnancy-united-states> (accessed July 24, 2018).

encountered these insensitive words, there is both opportunity and need for bereavement education among faith leaders, who are likely to counsel women and families after infant death. Again, like family planning, while incredibly important for supporting women and families, in and of itself increasing sensitivity and competency around bereavement does not seem to hold promise for having an effect on reducing the racial disparity void in infant mortality.

### **Support our Families: Steps toward Solidarity**

Amidst genuine frustration and despair about the dismal reality of infant mortality in our city, the collaborators to this project shared some hopeful messages about where they think we can go from here. When I asked Greg what his message would be to a room full of community partners involved in the Strong Baby Sanctuary program, he said:

Support our moms. I think that's the biggest thing, is that moms shouldn't have to do it alone. If you see someone who's pregnant, or has a new child, or even an older child, you should be offering help in whatever way you can. If you really want to affect the infant mortality in Milwaukee that's probably the best thing you can do. Supporting women, I guess, and infants. I don't know, I just want a better community, I think that's what we really need. A stronger community. And I think Milwaukee has some room to grow.

It is clear from Greg's statement that he feels that Milwaukee moms are not being supported as much as they could be. From his perspective, in order for this support to grow, Milwaukeeans as a community need to come together and take a stance. Reflecting on the conversations I had with each of the collaborators to this project, I believe each of them would agree with his statement here. However, these concepts of "support" and "growth" are a bit vague. What kinds of support are lacking in the lives of Milwaukee moms, and why are current programs and practices failing to meet their needs? What would it mean for Milwaukee as a community to grow to be able to meet these needs? In some way, each of the collaborators to this project were wrestling with these questions during our conversations. This section aims to distill their collective thoughts on

how Milwaukee's government, health systems, and community members can be involved in shoring up support for moms and infants.

**“We Fail as a Society”: Basic Health Care as a Human Right<sup>30</sup>**

Greg then brought up some important policy considerations that he thinks could make a strong impact in Milwaukee on infant mortality. He pointed to a recently proposed bill mandating drug-testing for Medicaid recipients, highlighting its potential to negatively affect pregnant women. When I asked him how he thought such a bill could be put into practice, he told me:

I have no idea. I didn't think of it, and I have not heard any logic that would make sense for putting that out. So I think that that would work very poorly. Now is it, 'Okay, the only way you can get health care is you get into treatment.' I don't know if there's that caveat, to be on drugs but in treatment to still get insurance. But if we just have a whole army of patients addicted to drugs and can't access health care, I think that's going to be an issue for our poorer patients generally. Certainly there is a middle-/high-end class on opiates who can afford health care on their own, but there are a lot of people on the street who can't. So that's going to be a huge effect. Especially if you have pregnant patients who can't establish care anywhere. And they're afraid of establishing care or are confused about establishing care if they're on drugs. Or God-forbid that they actually ban pregnant women who are on drugs from getting health care, I don't think they'll do that. That would be a crime against humanity. But who knows in our current political situation.

Here Greg is making a moral judgement about the necessity of health care for those who struggle with drug and alcohol addiction, especially pregnant women. There are many moral arguments that could support this line of thinking—not all of which necessarily support women's dignity and moral agency. For example, an argument for universal health care coverage for pregnant

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<sup>30</sup>Though debated in the US, health care is recognized as a human right in many places across the globe. The World Health Organization states: “The right to health is a fundamental part of our human rights and of our understanding of a life in dignity.” World Health Organization and Office of the United Nations High Commissioner for Human Rights, “The Right to Health,” <https://www.ohchr.org/Documents/Publications/Factsheet31.pdf> (accessed September 14, 2018).

women could be grounded in the rationale that health care access is in the best interest of the developing fetus and without this coverage, women cannot be trusted to care for and ensure the well-being of their unborn child. Greg is articulating a different message, grounded in the fundamental right to health care as a basic human necessity.

For Greg, this type of proposed legislature points to a fundamental discord in public moral perspective when it comes to health care:

We as a society need to figure out—we are currently debating, but not agreeing, on what is a basic level of human right that you are allowed. And at some point we decided that everyone deserves an education up through 12<sup>th</sup> grade. But we have also decided as a society that health care is not a right. I think that around half, or just over or just under half of our society, does not believe that health care is a human right. And I think that is affecting a lot of our health. I personally think that everyone should have a house—or a home—a roof over their head that's stable, and basic food, and basic health care.

This philosophical discussion being had in the public square on whether basic health care is a right has tangible consequences. Greg hypothesized that if pregnant women were to lose health insurance, those who are low-income—and most at risk for resorting to “selling their bodies” and “using needles if they don’t have access to health care”—would bear the heaviest burden. He thinks we could see public health epidemics related to increased HIV outbreaks, alcohol and drug abuse, unplanned pregnancies, and possibly more drug-addicted babies: all with the potential to contribute to increases in infant mortality and the racial disparities therein. For Greg, it is not only the government who has an important role to play; employers also share a responsibility. He pushes back against what he calls an “Amazon society,” where contract workers can be paid as-needed by the hour without receiving a living wage, consistent hours, and health insurance. In short, Greg concludes, “We fail as a society.”

Luke shared some ideas for health care policy improvements that could have an immediate effect on maternal and infant health for his patients. We talked about the example of a woman who does not have health insurance and is not able to access health care to help her manage chronic conditions like diabetes and hypertension. When she becomes pregnant, not only does she have these unmanaged conditions, but she also may not have had routine gynecological screenings like a pap smear recently, if at all. From a life course approach, understanding that the woman's unmanaged conditions are going to play a role in the likelihood of her having a healthy pregnancy, Luke responded, "So you're playing catch up from the first time they show up at your door." He then shared how for women in this situation, who were uninsured before pregnancy, that accessing insurance that a woman now qualifies for is a barrier:

The accessibility of insurance is something. If it becomes more difficult to get Medicaid or Badger Care, it's going to make it even more delayed for a lot of our patients to even get that first OB appointment. Most of them, by the time they schedule an appointment, they don't realize that if it's their first pregnancy they don't realize that this is a qualifying event for insurance. That is in itself a limiting factor for getting patients in. They don't realize that being pregnant qualifies you for BadgerCare, Medicaid.

Here Luke is referring to the fact that pregnancy counts as a qualifying event for Medicaid.

When a woman and any partner or children might not qualify on her own for Medicaid (given the threshold set based on the federal poverty line based on household size), being pregnant counts as another head in the household that may then qualify the family for Medicaid. Luke is referring to a first-time mom, and while a couple or single woman's income may float above the threshold for Medicaid, when another head is added, they qualify for Medicaid. Luke continues, "You have to know about health care to know that. I don't think that's public knowledge that you qualify for Medicaid when you are pregnant." This specialized knowledge, while probably not

common among the public in general, most negatively affects poor women and families. Luke sees a direct impact of health insurance accessibility on infant mortality:

If it becomes more difficult, If Medicaid is being cut, I only see that increasing our infant mortality rates because it's going to make it even more inaccessible for health care, not only for prenatal care, but for follow-ups, for newborn care.

### **Listening to Women and Understanding their Histories**

For Claire, a shift in bedside manner that puts the patient at the center of the prenatal visit is needed most. When I asked Claire if she had the full attention of a room full of doctors, what she would say to them that she thinks could have an impact on infant mortality. She stated:

I think for providers, taking your time, really listening to your clients, being respectful of them and their wishes and their wants. I think we do have some providers who really push for things like c-section, or are not really listening. I'm not saying this is all providers. We have some really great providers here in Milwaukee. But, I've also have my fair share of common providers—clients who have had the same providers. And, I don't wanna say complain, but they've had concerns about them. Like, 'Well they tell me I have to do this, but why is that?' But clients are kind of afraid to speak up for themselves. Sitting down, talking to their clients, and teaching them. Especially about things like contraception. And talking about options. And explain yourself. Don't just tell them, 'This is how it's going to be.' Really explain yourself. Really listen to the client.

It sounds simple: really listening to women about their health care values and concerns.

However in what Claire describes, much more is going on than presenting yourself as a passive sounding board. This kind of listening, when done well, can extend respect and trust, affirm the dignity present in the other, and send a message that a woman's own knowledge of her body and insight on what matters to her in her health care is the foundation of the relationship being built.

One final concept Katy brought up during our discussion that is fruitful for next steps toward solidarity is understanding how a particular patient's past affects their health in the present. Being knowledgeable about adverse childhood events and trauma-informed care is one



way to practice the life course approach to health, because it acknowledges how events from a woman's childhood can have effects into adulthood and pregnancy. The endorsement of trauma-informed care came up as Katy was providing an example of how she tries to share her experiences with other White people:

There's a lot of research now about the impact of trauma, and adverse childhood experiences, and in this circle everybody knows about it, but my friends who work at Northwestern Mutual don't know what 'ACES' or 'trauma' is. So trying to share that too. I have some friends that are teachers in suburban school districts, and it comes up a lot that if a Black family will move into there, it's always like 'Oh, these kids are so bad,' or 'they're so loud,' or 'they're so—,' so talking to them about, not only cultural differences, but also, 'What do you think that child experienced when he lived in inner-city Chicago, on the south side of Chicago, going to a public school, that was really different than yours.' And 'If he experienced trauma we know this is what it can look like in kids.' I've encouraged a lot of my friends to go to either the YWCA class, or trauma informed care—read up about it.

While Katy describes the importance of trauma-informed care for educators, it is increasingly being looked to as a necessary skill of health care professionals who serve underrepresented communities. More attention will be given to trauma-informed care and the positive role it can play in building solidarity between Strong Baby Sanctuary partners and the families they support in the next chapter.<sup>31</sup>

### **Additional Concerns and What I Did Not Hear**

The collaborators to this project discussed their concerns about many other topics related to maternal and infant health not addressed in this chapter. As I mentioned upfront, many of the health care professionals and church leaders I spoke with are keenly aware of the socioeconomic

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<sup>31</sup>"10 Key Ingredients for Trauma-Informed Care," Center for Health Care Strategies, Inc., <https://www.chcs.org/resource/10-key-ingredients-trauma-informed-care/> (accessed July 24, 2018). Trauma is described as "the events or circumstances experienced by an individual as physically or emotionally harmful or life-threatening, which result in adverse effects on the individual's functioning and well-being." More here or in next chapter.

stressors faced by Black women in Milwaukee, including limited financial means, inadequate housing, and exposure to violence, and single parenthood. Some discussed their experience that some women with unmet mental health needs turn to drugs and alcohol to self-medicate. One collaborator brought up the perspective that some clinicians push for medically unnecessary C-sections. All of the collaborators to this project in some way pointed out their awareness of the lack of social support they find when working with pregnant women and mothers. Though they will not be expanded upon here, how these experiences affect maternal and infant health and are complicated by the intersection of race, gender, and class may be fruitful for further research.

I find it interesting that abortion came up as a point of discussion with only one of the collaborators to this project—Luke—and this was within the context of informing pregnant women of all of their options. Luke explained to me that in order to present an open and unbiased approach to meeting a pregnant patient for the first time, he asks her, “What does this pregnancy mean to you?” After hearing her response, he is better prepared to provide his patient with the options that meet her goals and support her choices. His discussion could then proceed with information about abortion if the patient shared that she is considering that option.

Luke also shared with me a statement that may represent how good intentions can take on an air of paternalism that is subject to unconscious bias. When discussing birth control, Luke said,

The birth control thing is definitely a struggle, but we do push pretty strongly for it here just because we have a high risk population and we don’t want them to be in a financial situation that they can’t handle.

In a follow-up email, Luke clarified that by “a high risk population,” he was referring to the fact that the patients his clinic serves have high rates of unplanned or undesired pregnancies, and that

he “pushes strongly” to make sure that patients fully understand all of their birth control options.<sup>32</sup> Being aware of the characteristics of a patient population can provide insights into the kinds of health concerns that may arise and what questions could be helpful to ask, but this awareness needs to be balanced with specific attention to the particular patient. Luke stated that his clinic has taken to asking women “one key question,” a campaign that gears clinicians to ask all women of childbearing age whether she sees herself getting pregnant in the next year. Luke shared that if a patient answers “No,” he ensures she fully understands all of her contraception options, and if she answers “Yes,” he take the opportunity to have a preconception counseling appointment with her and talks about starting prenatal vitamins.<sup>33</sup> The “one key question” campaign is one example of this kind of attentiveness needed to balance public health concerns with practices that are respectful of individual patients. The concern for the patient’s financial situation gives pause. Certainly the woman herself, independent of her physician’s opinion, is in

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<sup>32</sup>Luke Williams, follow-up email to author, July 31, 2018. Luke also cited the following statistics: Unintended pregnancy rates are highest among poor and low-income women, women aged 18–24, cohabiting women and minority women; Rates tend to be lowest among higher-income women, White women, college graduates and married women. For example, in 2011, the rate of unintended pregnancy among higher-income White women was less than half the national rate (18 vs. 45 unintended pregnancies per 1,000 women aged 15-44); The rate of unintended pregnancy among poor women (those with incomes below the federal poverty level) was 112 per 1,000 in 2011, more than five times the rate among women with incomes of at least 200% of the federal poverty level (20 per 1,000); At 79 per 1,000, the unintended pregnancy rate for Black women in 2011 was more than double that of non-Hispanic White women; Women without a high school degree had the highest unintended pregnancy rate among all educational levels in 2011 (73 per 1,000), and rates were lower for women with more years of education; The proportion of pregnancies that are unintended generally decreases with age. The highest unintended pregnancy rate in 2011 was among women aged 20-24 (81 per 1,000 women); Traditional estimates understate the risk of teen pregnancy among adolescents because they typically include all women, whether or not they are sexually active. When rates are recalculated including only those sexually active, women aged 15-19 have the highest unintended pregnancy rate of any age-group; There are also disparities in the outcomes of unintended pregnancies across subgroups. In 2011, poor women had an unplanned birth rate nearly seven times that of higher-income women (those at or above 200% of the federal poverty level). Guttmacher Institute, “Unintended Pregnancy in the United States,” <https://www.guttmacher.org/fact-sheet/unintended-pregnancy-united-states#8> (accessed September 18, 2018).

<sup>33</sup>Ibid.

the best position to determine how a pregnancy could affect her financial situation. Given Luke's statements elsewhere, it is clear that he cares for his patients and supports women's autonomy and control over their bodies. However, even well-intentioned clinicians who are aware of the presence of race, class, and gender biases in practicing medicine are not immune to how these biases shape their clinical approach.

It was refreshing to hear that all of the collaborators to this project were aware that prematurity—not bed sharing or other parental behaviors—is the main cause of infant death. Additionally, they all had a good grasp of the multifactorial risks that can contribute to prematurity, which when considered together make the goal of a healthy baby decidedly outside of a pregnant woman's hands. While I did not necessarily expect to hear otherwise, I wondered whether I might see biases to the tune of “mothers behaving badly” play into our discussions. It did not appear that the collaborators to this project strongly link parental behavior with infant death. Even for those who brought up breastfeeding as an example of a healthy parental behavior they wish they saw more of, when I pushed back, asking if they thought an increase in breastfeeding might affect the infant mortality rate, the answer was a resolute “no,” and our discussion of underlying causes went back to the drawing board.<sup>34</sup>

The previous chapter made apparent the complex interplay of race, class, and gender in the daily lives of Milwaukee women when it comes to securing their health and the health of their children. This chapter affirmed the realities of the barriers they face, and more deeply

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<sup>34</sup>Breastfeeding did come up from a number of my collaborators. Greg Johnson shared his experience with me that while his wife received a lot of support with breastfeeding, he does not see that same level of nursing and lactation counselor involvement with his patients. He wonders if race and class have anything to do with how much support (or not) is provided for African American women when it comes to breastfeeding. This topic is fruitful for future work in an article or chapter outside of this dissertation.

complicated perceptions about root causes, underlying biases, and potential solutions. Each of the collaborators to this project introduced in this chapter shared some level of understanding of the lived struggle of their clients and patients, which is an important starting point for the journey toward solidarity. Their insights on the complexities of the intersection of race, class, and gender when it comes to women's and infant health have important considerations for those who have decision making power—whether in health systems, the government, or in churches—when it comes to directing initiatives and changing approaches aimed at lowering infant mortality.

The next chapter will introduce a discussion of concrete practices that address the barriers to women and infant health identified by the collaborators to this project. Some examples include models of prenatal care like “The JJ Way” and Centering Pregnancy that foster a supportive environment, peer support, and thwart social isolation; the opportunities of training all health care professionals in a clinic and hospital on Trauma-Informed Care and ACES; and the important role community health workers and para-professionals can play in supporting women's agency and building trust with the medical community. Focus will then turn to how these practices compliment the core principles of Christian bioethics set out in Chapter Two. Then, recommendations will be made for Strong Baby Sanctuary partners regarding how these practices can help inform and re shape their practices as they work together to close the racial disparities gap in infant mortality.

CHAPTER FIVE

CONTEXTUALIZED SOLIDARITY IN RESPONSE TO MILWAUKEE'S  
INFANT MORTALITY CRISIS

As White feminist Christian ethicist Karen Lebacqz observes, “Justice emerges as the cry of revolt against injustice. An approach to justice must therefore begin with injustice.”<sup>1</sup> Recognizing failures of justice can help us discern where to start imagining what is needed to create a more just society. In this work, I have shown how a prime example of injustice is the false narrative that Black parents are to blame for the disproportionate infant mortality rate of Black infants. The fact is that the majority of Black infants die due to causes related to prematurity. Prematurity is not solely or even mostly within a pregnant woman’s control, and there is a racial disparity between Black infants and those of other races who die due to prematurity. The fact that Black women with graduate degrees have worse birth outcomes than White women who haven’t finished college demonstrates how race itself and structures of racial injustice play a major role.

Therefore since it is not unsafe sleep but prematurity that is causing racial disparities and the vast number of Black infant deaths, and since we know that the reasons underlying prematurity include racialized structures of disadvantage that affect socioeconomic factors and women’s health, it is not only inaccurate to say that Black parents are to blame, but it is a failure to stand with Black parents and demand better for their children. Narratives that locate

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<sup>1</sup>Lebacqz, *Justice in an Unjust World*, 10.

Milwaukee's infant mortality crisis within "the Black community," or focus disproportionately on safe sleep or maternal health without addressing social and racial determinants to a proportionately higher degree, are glaring illustrations of a basic failure on the part of health care providers, public health policymakers, and church members to understand, let alone target, the root causes of the problem. Moreover, when health care providers, public policy officials, and church outreach programs start with these assumptions when trying to reach Black women at risk of having a child who dies before turning a year old, even if our efforts are well-intentioned, they are nonetheless examples of failed solidarity.

In short, we need to develop a much richer understanding of what it means to practice solidarity in the particular context of addressing racial disparities in infant mortality in Milwaukee. The kind of solidarity we need will be historically conscious, and aware of power dynamics at the intersection of race/class/gender. It will also need to be attentive to the particular everyday lives of Black women, men, and children. We must start by looking at the violence and disrespect that lie at the heart of many of the experiences shared by the collaborators to this project. Each collaborator's insight can help shape a contextual solidarity that can be relevant for addressing racial disparities in infant mortality.

An ethic that prioritizes infant lives must prioritize the health and well-being of Black women. We cannot reduce the number of infant deaths without tackling the underlying causes of the racial disparities that cause infant mortality rates to remain stubbornly above national and local targets. Statistical analysis and qualitative studies introduced in this work point to social structures that perpetuate disparities based on race, class, and gender and that contribute to toxic stress, poor health, premature births, and ultimately infant deaths. Black women who are at the

intersection of these social identities are disadvantaged when it comes to healthy birth outcomes when compared to their White and Hispanic counterparts, and therefore attention to their health warrants proportionate concern.

Prioritizing the health of Black women does not come at the expense of the health of others. Conversely, the factors that are important for Black women's health are integral to the health of all women and families. It just so happens that the list of things that can go wrong in any pregnancy go wrong more often if the way you go through life is shaped by your race and gender as a Black woman in the cultural milieu of 21<sup>st</sup> century US. If you also happen to be under-resourced financially, the intersecting social reality of class status further compounds the stressors one experiences that are bad for moms and babies. To meet the goal of helping more infants reach their first birthdays, we need guidance from bioethical frameworks, principles, and practices rooted in an understanding of the intersectionality of social location and how relationships between Black women and health care providers, government agencies, and churches are shaped by the power dynamics inherent in US culture.

Further, people who hold positions of power within health care institutions, governmental and social services agencies, and faith communities have additional work to do. We are charged with not only taking a deeper look at social determinants of health and how race/class/gender complicates so much of the underlying picture contributing to infant mortality, but also owning up to our complicity in perpetuating ideas and approaches that have failed to truly see and respond to the havoc wreaked by racism, classism, and gender inequity. This is no easy task. This kind of critical self-reflexivity involves considerable time and effort dedicated to taking a look at how Whiteness privileges us in our daily lives, and cultivating the self-awareness to



recognize when and how our (albeit well-intended) decisions are marred by race, class, and/or gender privilege (among other privileges as well).<sup>2</sup> A solidarity approach to the problem of infant mortality in Milwaukee will take extra work and action on the part of individuals and social institutions with privilege at the intersection of race/class/gender.

Specifically, we need a White anti-racist approach to solidarity on the part of those White people with the decision making power to change the landscape underlying infant mortality.<sup>3</sup> This framing of solidarity necessitates that White people play a supportive, instead of a leading, role that regards critical self-reflection as highly as it does partnership with Black leaders for the cause. Part of this self-evolution will necessitate learning lessons from failed solidarity.

One example is the Women's March, boycotted in 2017 by some women of color who critiqued the previously all-White leadership for not prioritizing intersectional approaches to feminism and failing to contend with the fact that 53% of White women voters voted for Donald Trump, who vowed to dismantle the Affordable Care Act as well as advance other policy decisions that would hurt Black women and families.<sup>4</sup> A White anti-racist approach admonishes

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<sup>2</sup>There are many other privileges that those in positions of decision making power regarding infant mortality may hold based on age, religion, ethnicity, ability/disability, etc. These are important to interrogate as well. Chapter Two made a case for how race, class, and gender are particularly relevant to the problem of infant mortality in Milwaukee.

<sup>3</sup>There is particular work that needs to be done especially by White people in places of social power to address their privilege. White fragility is a term currently used to capture how many White people currently approach discussions about race and racism: we are defensive, experience emotions including anger, fear, and guilt, and without having developed constructive ways to dialogue about race, we fall back on argumentation or silence. See Robin DiAngelo, *White Fragility: Why It's So Hard for White People to Talk about Racism* (Boston: Beacon Press, 2018).

<sup>4</sup>Paula Rogo, "Why are Some Black Women Skipping this Year's Women's March?" *Essence* (January 20, 2018), <https://www.essence.com/culture/black-women-boycott-womens-march/> (accessed December 5, 2018); Karen Grigsby Bates, "Race and Feminism: Women's March Recalls the Touchy History," *Code Switch: Race and Identity Remixed*, National Public Radio, January 21, 2017, <https://www.npr.org/sections/codeswitch/2017/01/21/510859909/race-and-feminism-womens-march-recalls-the-touchy-history> (accessed November 13, 2018).

us to learn the history of the sanctioned dehumanization of Black and brown families by White people and institutions in our own backyards, and how the effects persist today. It also compels us to sit with the unease of unearned, unjustified privilege, and together with other White people interrogate what constitutes an adequate response. Importantly, White people trying to act in solidarity with Black families need to recognize and call attention to the longstanding groundwork and ongoing activism by Black women and men that has been vital to bringing attention and support to Black families affected by infant mortality. A White anti-racist approach to solidarity has the potential to create the kind of change needed to support all mothers and babies by prioritizing the well-being of Black women and their infants.

This chapter reflects upon the question, “What should solidarity look like in the context of disparities in infant mortality in Milwaukee?” To get at this question, first I will explore what failed solidarity looks like as informed by the experiences of the collaborators in this study. Their insights set the stage for what solidarity will need to attend to in this particular context. Next, I will describe what contextualized solidarity ought to look like, including descriptions of its key components. Finally, I will suggest recommendations for taking steps toward this kind of solidarity for health care providers and health system leaders, public health policymakers, church volunteers, and bioethicists.

### **Failed Solidarity**

It is clear that Black women in Milwaukee experience dehumanization and disadvantage. Underlying these realities are Black women’s relationships with health care providers, social and governmental agencies, and community groups and individuals whose lack of understanding of the power dynamics at the intersection of race, class, and gender leads to failed solidarity.

Additionally, practices and policies enacted by those with good intentions but that lack critical self-awareness ultimately do a disservice to Black women and families. Failed solidarity includes our reluctance to take action and ultimately our absence from practices that have promise for correcting these imbalances. By recognizing particular instances of failed solidarity throughout the experiences shared by the collaborators to this project, we can begin to flesh out starting points for the types of changes needed to work toward true solidarity and just relationships.

Solidarity is the internalization of the interconnectedness and mutual interdependence of individuals or groups on a local or even global scale with the recognition that systemic power imbalances have direct and meaningful effects on others, and that those who benefit are charged with work toward more equitable circumstances for all. As emphasized by Catholic social ethicist Tisha Rajendra and Christian social ethicist Laurie Johnston, “[g]enuine solidarity must include specific practices that manifest an enduring commitment to particular groups of suffering people.”<sup>5</sup> Following this rationale, members of a given community are accountable to seeking the good of others, and are responsible for correcting wrongs. When attentive to social power dynamics, solidarity is exemplified by those in power accepting responsibility for historical inequities and recognizing complicity in perpetuating disadvantage. Failed solidarity, then, can be recognized as the inability and unwillingness of those of us who benefit from unequal power dynamics to recognize the shared dignity present among those who are disadvantaged by these same structures. Failed solidarity also includes the failure to act to correct injustices. While solidarity in the universal sense will harbor these characteristics, solidarity will inevitably look

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<sup>5</sup>Tisha Rajendra and Laurie Johnston, “Ambivalent Solidarity,” in *Public Theology and The Global Common Good: The Contribution of David Hollenbach*, ed. Kevin Ahern et al (Maryknoll: Orbis Books, 2016), 121.

differently based on the particularities of the relationship between oppressed and oppressor groups in different contexts.

The disproportionate amount of stress Black women in Milwaukee face compared to their White counterparts is a measure of failed solidarity. Recall the common thread of experiencing violence shared by the Milwaukee mothers who spoke with me, and how Gaia (nurse, program coordinator, and grandmother) accurately pointed out that Milwaukeeans experience more violence than those who live in other cities.<sup>6</sup> The fact that this violence continues year after year means that too many in Milwaukee failed to show genuine solidarity with those suffering disproportionately from it. Lack of insight into how social inequities correlate to violence prevalence is another failure: it is irresponsible to overlook how the lack of jobs that pay a living wage and the disproportionately low high school graduation rates contribute to the prevalence of violence and high incarceration rates. Moreover, inattention to the systemic nature of racism and the role racism plays in perpetuating the cycle of violence allows continued blame for infant mortality to be misplaced at the feet of Black women and families. When viewing violence through the lens of trauma-informed care, we must come to acknowledge it as a social determinant that can have cyclical and generational effects on family structures and communities to the detriment of women's and infant health.<sup>7</sup>

Discrimination based on race and class is another stressor faced by Black families in Milwaukee that represents failed solidarity because it means that those in relative social power, especially White people, continue to dismiss the perspectives and experiences of people of color.

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<sup>6</sup>See page 108.

<sup>7</sup>H. Westley Clark, "Women, Co-occurring Disorders, and Violence Study: A Case for Trauma-Informed Care," *Journal of Substance Abuse Treatment* 28, no. 2 (March 2005): 145-146.

For example, the collaborators in this research referred to the experience as being made to feel “less than” when interacting with health care institutions and social services agencies. Sister Faye, Strong Baby Sanctuary group leader and a Black woman, told the story of her nephew, also Black, waiting in an Emergency Department for long periods of time in excruciating pain before being seen. While she could not be sure that his wait was due to the dismissal of his pain because of his skin color or insurance status, it seemed to me that Sister Faye would not have been surprised if this were the case. Oppression at the intersection of race, class, and gender can be especially demeaning. Recall Missy’s lament that “society makes Black people look so bad,” and that social service agencies “make you feel less of a human being.”<sup>8</sup> Each of these instances represents failed solidarity on the part of those who occupy different social locations, because they have failed to recognize that they benefit from a system that perpetuates the dehumanization of Black women that manifests as toxic stress in their lives.

Another example of failed solidarity discussed by these collaborators stems from paternalism in medicine. Paternalism is described as “the tendency to treat otherwise capable adults as though they were children in need of others to make decisions for them.”<sup>9</sup> The danger of paternalism is that the false confidence of knowing what is best for a patient despite her particular values and agency in putting them into practice in her health care decisions. It is a particularly a problem in health care contexts because of the uneven power dynamics between clinicians and patients. Indeed, the inherently uneven balance between patient and health care professional can be pushed even more off-kilter when affected by embedded structures of race,

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<sup>8</sup>See page 145.

<sup>9</sup>Linda Farber Post and Jeffrey Blustein, *Handbook for Health Care Ethics Committees*, 2<sup>nd</sup> ed. (Baltimore: Johns Hopkins University Press, 2017), 23.

class, and gender bias. Remember Strong Baby Sanctuary group leader Missy's experience of feeling disrespected by her son's NICU nurse. When Missy shared her hope that her son would be discharged in a few days, the nurse gave her opinion that Missy's son was unlikely to go home anytime soon. It seems to me that the reason Missy was upset by this exchange was not what the nurse said, but how she said it. While the nurse could have said something like, "I hope so too, but let's talk more about what the doctors predict will happen in the next week," the real exchange happened within the paradigm of "nurse knows best" when it comes to Missy's son.<sup>10</sup>

This patient-clinician power dynamic must also be viewed through the lens of historical consciousness, or the recognition and understanding of how today's social structures are shaped by injustices of the past. In the context of medicine, historical consciousness means to be attentive to the abuses Black women have historically experienced in the name of medicine and research, and how they have historically been treated by institutions of medicine and health care professionals, and how this history has led to disparities in care based on race. This paternalistic framing not only usurps the mother's role in knowing what is best for her child, but feeds toxic stereotypes discussed in Chapter Two. Missy ended up feeling disempowered as a mother and a woman instead of being invited to partner with her nurse and together consider her son's situation. Instead of finding a way to balance hoping for the best with being prepared for a longer NICU stay, the easy and familiar narrative of paternalism framed the nurse's response to Missy's goal for her son.

Also recall that Claire Smith, home visiting nurse with the health department, shared that many of her clients do not feel like their prenatal care providers listen to them. Overlooking the

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<sup>10</sup>See pages 146-147.

health care values and social contexts of particular women can have detrimental effects on the patient-clinician relationship, even when her medical history is clear. This inattention and unwillingness to listen blockades the possibility for shared decision making to take place, and demarcates a stunted beginning for the development of a trusting relationship.<sup>11</sup>

In a related vein, Claire is also concerned that some providers may pressure women into certain birth control options or procedures like scheduled C-sections based on what can be billed for at a higher rate and more easily be scheduled. Here solidarity has failed not only because “doctor knows best,” but also because the clinician has put her needs and values over that of the patient’s. Hubris may play a part too if clinicians are downplaying or overlooking higher risks of certain options in favor of convenience for themselves.<sup>12</sup> Structural dynamics of health care reimbursement play a role as well: if C-sections were reimbursed at a rate more commensurate with vaginal births, perhaps clinicians would think differently about the risks and benefits of a scheduled C-section based on the patient’s particular history, values and preferences.

Nurse and Strong Baby Sanctuary group leader Gaia shared her experience of feeling disempowered as a woman and a leader in her church. At one time she had wanted to bring some educational programming about health and wellness topics to her (now former) church. She explained,

It was a Church of God in Christ, a sanctified Pentecostal church, so it had a lot of different beliefs, and especially beliefs concerning women, that I just could not deal with

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<sup>11</sup>Susan Dorr Goold, “Trust, Distrust and Trustworthiness,” *Journal of General Internal Medicine* 17, no. 1 (January 2002): 79-81.

<sup>12</sup>Recall this description of hubris I offered in Chapter Four: Hubris can be understood as a sense of arrogance about the expertise of science and medicine while ignoring harms caused by evidence-based practices throughout history as well as the realities of present-day unknowns.

that any longer, and my choice was not to participate in it, that form of organized religion.<sup>13</sup>

Here Gaia may be referring to the fact that COGIC does not ordain women, which sets up an unequal power dynamic between men and women in leadership that has an effect on how a congregation understands gender roles. Of course, Gaia's experience with the COGIC is not representative of all women's experience of this denomination; indeed, many women have contributed positively to the history of COGIC and find it to be a source of empowerment.<sup>14</sup> Even within denominations whose canons speak to the equality of women and men in leadership roles and all aspects of life, practices within particular churches can and do lean toward the long history of marginalization of women within the Christian tradition. It is important for all churches who seek to support marginalized women to be cognizant of this history, so that those like Gaia who want to empower women from a faith-based place can be supported.

In all, the collaborators point to a variety of failures to engage in relationships of solidarity with Black women and their families. There are indeed other experiences they shared that could fit here too: the way White privilege affects how White clinicians treat Black women; the lack of support for dads; conflicting messages about family planning and mixed messages from churches all represent falling short of solidarity, all of which are discussed in more detail in Chapters Three and Four. Indeed, there are many areas for improvement. Despite these failures,

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<sup>13</sup>Gaia Earth, focus group interview by author, Milwaukee, WI, July 29, 2017.

<sup>14</sup>Anthea D. Butler, *Women in the Church of God in Christ: Making A Sanctified World* (Chapel Hill: University of North Carolina Press, 2007).



my collaborators also shared examples of relationships where the beginning seeds of solidarity were taking root.

### **Key Components of a Contextualized Solidarity**

By recognizing failed attempts at solidarity, we can come to envision what a contextualized solidarity relevant to infant mortality in Milwaukee might look like. This section brings forth solidarity as a principle that is historically-minded, conscious of race/class/gender disparities, and that begins with the recognition of specific injustices in our midst. In what follows, I will describe foundational components of a solidarity that is attentive to the struggles of Black women in Milwaukee. This contextualized solidarity rests upon a principle of respect for persons that affirms the dignity of all by prioritizing those who have been put last and supports the agency of those most often disadvantaged. It is also formed by the recognition that for authentic solidarity to take root, those of us in places of power need to account for our own failures and the failures of the institutions we represent to respect and care for those most often neglected. This kind of solidarity will necessitate a *metanoia* or a change of heart for those who benefit from privilege at the intersection of race, class, and gender. Compassion, or the cultivation of empathy to such an extent that motivates action on behalf of the unjustly disadvantaged other, is integral to this conversion. Finally, mutuality and accompaniment will be described within the context of the needs of Black women, infants, and families in Milwaukee, and presented as key components of solidarity.

### **Respect for Black Women's Dignity and Agency**

Underlying the examples of failed solidarity above is the failure to adhere to a context-specific principle of respect for persons. The troubling truth is that the degree to which a person

is respected in interactions with social and health care institutions often correlates to how much privilege their social location offers. What does it mean to truly respect someone in a social services or health care encounter? An important factor in the experiences of collaborators to this project was whether or not they felt respected. Specifically, encounters that affirmed a woman's dignity and agency—like a relationship with a mental health provider who listened and understood—embodied respect, while encounters with social service and health care institutions that degraded and depreciated women conveyed disrespect. A contextualized principle of respect for persons that can carry meaning particular to the situation of infant mortality in Milwaukee is a principle of respect for Black women's dignity and agency. Given the aim to describe a principle of respect that can build solidarity with Black women, we would do well to turn to the body of scholarship in feminist and womanist thought to broaden and deepen this principle.<sup>15</sup>

A principle of respect for Black women's dignity and agency is in part a feminist critique of misunderstandings of the Belmont principle respect for persons and the derivative bioethical principle respect for autonomy. Recall, as cited in Chapter Two, Lebacqz's lament that respect for persons, reinterpreted as respect for autonomy, has now been whittled down to "freedom of choice" in common language. It appears that the undergirding concept of undeniable regard for

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<sup>15</sup>Worthy of more work after this dissertation is mining the womanist tradition to more fully flesh out a bioethical principle of respect for women's dignity and agency. Publications by womanist scholars that are integral to this work include: Katie Geneva Cannon, *Womanism and the Soul of the Black Community* (New York: Continuum), 1998; Katie Geneva Cannon, Emilie M. Townes, and Angela D. Sims, ed., *Womanist Theological Ethics: A Reader* (Louisville: Westminster John Knox Press, 2011); Patricia Hill Collins, *Black Feminist Thought: Knowledge, Consciousness and the Politics of Empowerment* (London: Routledge, 2000); Copeland, *Enfleshing Freedom*; Kimberle Crenshaw, "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color," *Stanford Law Review* 43, no. 6 (July, 1991): 1241-1299; Kelly Brown Douglas, *Stand Your Ground: Black Bodies and the Justice of God* (Maryknoll: Orbis Books, 2015); Diana Hayes, *Standing in the Shoes My Mother Made: A Womanist Theology* (Minneapolis: Fortress Press, 2010); Townes, *Womanist Ethics*; Delores S. Williams, *Sisters in the Wilderness: The Challenge of Womanist God-Talk* (Maryknoll: Orbis Books, 1995). The work of White scholars engaging womanist thought would also be helpful, e.g. Karen Teel, *Racism and the Image of God* (New York: Palgrave Macmillan, 2010).

human dignity has been usurped by a political image of uninhibited freedom. Certainly this image has particular meaning in the US context, where our Constitution reifies the right to life, liberty, and the pursuit of happiness as a celebration of independence. However, narrowing a principle of respect for persons to independence without considering its twin, interdependence (which is just as constitutive of the human condition), fails to provide a full picture of what it is about a person that ought to be respected. Additionally, mistakenly understanding this principle as “respect for independence” fails to take into account how social structures unjustly constrain the moral agency of those put at disadvantage by imbalances in power relations.

In the medical world, too often health care leaders, clinicians, and frontline staff presume they know what it means to treat someone with respect without reflecting on how the multiple biases they harbor might be shaping their attitudes and actions. These missteps, often due to unconscious biases stemming from difference in class, education, and even the value placed on Western medicine, can serve to embolden already present power dynamics and create experiences of disrespect on the behalf of patients. Lebacqz’s thoughts on righting these unjust relationships—in this case, unequal power dynamics in the patient-clinician relationship and the health care system as a whole—are directive here. She astutely observes:

The lesson to be learned from those who are relatively powerless is that we need changes in the system, not just changes of attitude in a few care-providers. More thoughtful listening, a willingness to hear the “whole” story and not just the “salient facts,” will still be important. But it is the system that must be scrutinized for how it disempowers those who are already powerless, and how it could be made more empowering instead.<sup>16</sup>

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<sup>16</sup>Karen Lebacqz, “Empowerment in the Clinical Setting,” in *On Moral Medicine: Theological Perspectives in Medical Ethics*, ed. M. Therese Lysaught et al. (Grand Rapids: Eerdmans Publishing Company, 2012), 319.

While dignified and respectful care may be goals outlined in a health care system's mission statement, it takes both individual patient-clinician encounters and changes in the way health care is delivered to make these goals achievable. Respect for Black women's dignity and agency, then, ought to promote both changes in interpersonal relationships and in structural power imbalances that disadvantage Black women and families.

What does it mean to have respect for dignity and agency? Dignity can be understood as that inherent and inalienable reflection of the *imago Dei* in each and every person, requiring their recognition as a person of incommensurable value and care that necessitates each person is treated as an end in themselves and never as a means toward an end. Agency is that quality of the human person to perform and direct her moral life, to be the author of her life story, which includes considering complex tradeoffs and making difficult choices. Agency can be thought of as an important aspect of dignity, along with these qualities of relationality interdependence, and vulnerability. These universalistic descriptors are helpful as litmus tests for whether respect for dignity and agency is taking place, however what this looks like in particular situations depends on the context. What does it mean to have respect for Black women's dignity and agency in the context of infant mortality in Milwaukee?

Womanist insight is fruitful for shaping a principle of respect for Black women's dignity and agency that is contextualized to this situation. Centrally, womanist thought demands that women are taken seriously as moral agents: responsible for and in charge of their own life plans. Agency is incredibly important in womanist thought: Alice Walker's landmark description of a womanist lifts up multiple character traits that specifically relate to a Black woman's moral

agency and role as change agent in her social world.<sup>17</sup> Respecting a Black woman as an embodiment of the image of God—and therefore deserving of the utmost trust when it comes to evaluating and directing the course of her moral life—can have a significant impact on reframing approaches to women’s and infant care.

Womanist thought is also skeptical of individualistic interpretations of a respect for person’s principle. Concerning the truncating of respect for persons to “freedom of choice,” womanist ethicist Emilie Townes finds this “myth of universal uninhabited freedom” especially problematic given the history of race relations in our country. She astutely points out that this myth “has always had its evil twin—studied sadistic subordination and annihilation.”<sup>18</sup> Here she is referring to the fact that while White men in the US have always been afforded freedom, Native Americans, African Americans, women of all races, and others have faced dehumanization at the expense of the freedoms of others. To ensure that we do not uphold respect for some at the expense of respect for others, we must reimagine a principle of respect for persons or respect for autonomy that is broader than this myth of individual entitlement. A principle of respect for Black women’s dignity and agency helps reframe what is essential about respecting persons when it comes to building solidarity with Black women in Milwaukee.

Following Townes and Lebacqz, a principle of respect for Black women’s dignity and agency must address the complex social context that complicates how individual women make decisions. It must be able to balance both that women’s choices are often shaped by interdependence, vulnerability, and social constraints, and that this shaping in no way diminishes

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<sup>17</sup>Alice Walker, *In Search of Our Mothers’ Gardens: Womanist Prose* (San Diego: Harcourt Brace Jovanovich, 1983).

<sup>18</sup>Townes, *Womanist Ethics*, 109.

their status as moral agents and the inherent dignity they possess. Here it is helpful to consider that different strands of feminism have offered caring, mutuality and vulnerability as common facets of women's moral experience that help us describe what it means to be human and what attributes are recognizable as dignity-affirming characteristics of moral agents. These qualities of human experience uplifted by feminist inquiry are expressed differently in individual women's lives, and are morally complex. For example, Lebacqz posited, "Will lifting up the value of caring return women to the confining roles of the past, or will it open up new vistas in ethics and in bioethics? This is the current challenge for feminism and bioethics."<sup>19</sup> Here Lebacqz points out how the role of caring is morally complex and is not able to be isolated from historical structures of power imbalances based on gender. Like caring, mutuality and vulnerability are not immune from being co-opted by unbalanced power dynamics, but they are still important starting points gleaned from women's experiences that can provide context for understanding and respecting the particular moral lives of women, men, and families.

Indeed, while these qualities like caring, mutuality, and vulnerability are, to a degree, common to the human condition, each of them can also be intensified or downplayed by social conditions. Catholic, German feminist ethicist Hille Haker categorizes these different manifestations of vulnerability as ontological, moral, and structural.<sup>20</sup> For example, some vulnerability is part of the human condition, but there is also vulnerability perpetuated by social structures that affects those disempowered by unbalanced relationships at the intersection of

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<sup>19</sup>Karen Lebacqz, "Feminism and Bioethics: An Overview," *Second Opinion* 17, no. 2 (October 1991).

<sup>20</sup>Hille Haker, "Vulnerable Agency—Human Dignity and Gendered Violence," in Jonathan Rothschildt and Matthew Petrussek eds., *Dignity and Conflict: Contemporary Interfaith Dialogue on the Value and Vulnerability of Human Life* (Notre Dame: University of Notre Dame Press, 2019), 393-436.

race, class, and gender more so than others. When the social location of women makes them vulnerable, dependent, self-giving, and caretakers of everyone else to extremes that are to their own detriment, agency is not enhanced, but constrained. Black women living in under-resourced contexts may feel that the vulnerability they experience is far beyond that which is normal to the human condition. They may experience that their comparatively deeper vulnerability is taken advantage of and exploited. Having deep vulnerability, however, does not silence Black women's voices or halt their moral action. As Haker states,

Excluded or marginalized groups, the ethics of vulnerable agency claims, are not only passive victims of injustice; that their voices are not heard does not mean that they do not *have* voices or agency but, rather, that they are *silenced* by a code of honor that is embedded in social norms.<sup>21</sup>

So it is that the same social structures that perpetuate this kind of vulnerability also makes it normative that Black women's voices are not heard and that their actions are not noticed. A principle of respect for Black women's dignity and agency needs to be able to navigate the tension between women's vulnerability that is part of what it means to be an interdependent person, and that which is unjustly cast upon them by unbalanced social structures.

When it comes to the particular situation of confronting racial disparities in infant mortality, a focus on mothering as a moral act is also warranted. Often, the response among health care and social services circles to the call to empower parents is to give them more education about safe and healthy infant- and self-care practices. Black feminist and sociologist Patricia Hill Collins provides a framework for understanding that feeling empowered as a Black mother is far more complex than having the right information. At the very least, the first step is

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<sup>21</sup>Ibid., 412.

to listen to each individual Black woman about what mothering means to her. Collins presents a nuanced picture of the varying effects being a mother can have on individual Black women, which affects how they see themselves as moral actors:

Black motherhood as an institution is both dynamic and dialectical. Ongoing tensions characterize efforts to mold the institution of Black motherhood to benefit intersection oppressions of race, gender, class, sexuality, and nation and efforts by African-American women to define and value our own experiences with motherhood. The controlling images of the mammy, the matriarch, and the welfare mother and the practices they justify are designed to oppress. In the context of a sexual politics that aims to control Black women's sexuality and fertility, African-American women struggle to be good mothers. In contrast, motherhood can serve as a site where Black women express and learn the power of self-definition, the importance of valuing and respecting ourselves, the necessity of self-reliance and interdependence, and a belief in Black women's empowerment. These tensions foster a continuum of responses. Some women view motherhood as a truly burdensome condition that stifles their creativity, exploits their labor, and makes them partners in their own oppression. Others see motherhood as providing a base for self-actualization, status in the Black community, and a catalyst for social activism. These alleged contradictions can exist side by side in African-American communities and families and even within individual women.<sup>22</sup>

Collins points out that while motherhood is a shared experience, mothering can carry vastly different meaning from woman to woman. What is common is that how an individual Black woman experiences motherhood is inevitably shaped by social stereotypes and stigmas about Black mothers that work to disempower Black women. While one Black woman might find power and encouragement from the experience of mothering, another may find it stifling to her development, and many may fall somewhere in-between or experience both feelings at once.

While some toxic stereotypes of motherhood affect White women too, the overwhelming burden of racial stereotypes steeped in a three hundred year plus history of chattel slavery make the experiences of Black mothers uniquely fraught with moral tensions. White women trying to

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<sup>22</sup>Collins, *Black Feminist Thought*, 176-177. See further discussion in Chapter Two, pages 66-69, about the ubiquitous influence of these kinds of stereotypes and the harm they do to Black women and families.



engage in anti-racist solidarity with Black women need to see that being a mother is more complex for Black women because of an ongoing social commentary specific to Black moms that as White women we cannot fully understand. This kind of awareness into the complexity of what mothering might mean for a particular Black woman can help others in places of social power be more thoughtful about what it might mean to support a mother's agency. Noticing and appreciating the complexity of the meaning of motherhood for a Black woman as she navigates the moral challenges of being a mom will be a necessary part of respect for Black women's dignity and agency.

Collins then introduces five enduring themes of motherhood that represent experiences among Black women that can be helpful to inform different ways agency might be best supported in individual Black women's lives. She is careful to note that these five themes do not present a normative framework by which to measure mothers, but instead are interconnected yet distinct "lifelines" guiding Black women as individual moral agent as they navigate their personal standpoints on motherhood. For example, while the theme "motherhood as a symbol of power" uplifts the possibility of mothering to empower women, the theme "the personal meaning of mothering" speaks to the many ways in which being a mother is unique to the individual woman's situation and can take on different degrees of moral meaning. The theme "bloodmothers, othermothers, and women-centered networks" highlights how mothering can include care and responsibility for other children, women, and men outside of biological relationships.<sup>23</sup> "Community othermothers and political activism" connects this broadened view

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<sup>23</sup>Collins notes, "Biological mothers, or bloodmothers, are expected to care for their children. But African and African-American communities have also recognized that vesting one person with full responsibility for mothering a child may not be wise or possible. As a result, othermothers—women who assist bloodmothers by sharing motherhood responsibilities—traditionally have been central to the institution of Black motherhood."

of the moral purview of mothering to its fittingness for action for social justice. Finding out how an individual Black woman identifies with one of these themes of motherhood—or attributes their own personal values to their experience of mothering—can help those around her recognize and remove barriers to her being able to perform as she would desire as a mother and moral agent in her social world.

Taken together, these themes are fruitful for considering what a contextualized solidarity rooted in a principle of respect for Black women’s dignity and agency can look like in response to Milwaukee’s infant mortality crisis. Attention needs to be paid to removing barriers to Black mothers garnering the social power necessary to flourish as moral agents. Collins asserts that “[m]otherhood—whether bloodmother, othermother, or community othermother—can be invoked as a symbol of power by African-American women engaged in Black women’s community work.”<sup>24</sup> Black motherhood, broadly conceived in this way, can be accessed as a source of power for those motivated to make positive change in their community. In this way, Black motherhood becomes a well of social power that can work toward social justice.

How can those with social and economic power and racial privilege support the social power of Black motherhood, broadly conceived? Collins includes recommendations for how “[n]ot just Black women but those who care about Black women can also access the power associated with activist mothering.”<sup>25</sup> She provides the example of how racist environments

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Examples of othermothers include Grandmothers, sisters, aunts, and cousins, as well as “fictive kin” and neighbors, both women and men, who take on child-care responsibilities. In this way the community takes on responsibility with mothers for collectively raising children. *Ibid.*, 178.

<sup>24</sup>*Ibid.*

<sup>25</sup>*Ibid.*, 194.

shape motherhood for White mothers of biracial children, emboldening them to become politicized activists on behalf of Black children.<sup>26</sup> Massingale also points to how the experience of being a White parent of Black children opens one's eyes to the realities of racism and becomes a motivator for action toward solidarity.<sup>27</sup> Though not suggesting one has to be married to or parent of someone of a different race to honor their dignity and support their agency, these special relationships that push the socially-constructed bounds of race can offer bridges to thinking differently about what it means to be on the side of someone of a different race.

An important step toward respect for Black women's dignity and agency is listening to and trusting Black women. While insufficient on its own, listening to and trusting Black women is nonetheless necessary for realizing a commitment to this principle. Listening—actively, empathetically, and mindfully listening to a particular woman's life story and history—was identified by many of the collaborator to this project as a key component of building trust with women.<sup>28</sup> It is significant that Claire and Katy—whose roles as home visitors offered them both a longer duration of visit and a longer timeframe over which a relationship could develop when compared to my physician collaborators—emphasized concerns over the need to listen to women and understand their histories. Building trusting relationships takes time. Luke mentioned that as a family medicine physician he is allotted more time during clinic visits with pregnant patients

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<sup>26</sup>Ibid.

<sup>27</sup>Massingale, *Racial Justice in the Catholic Church*, 119-120.

<sup>28</sup>The relationship between listening and trust is reflected in the literature, e.g., Monica E. Peek et al, "Patient Trust in Physicians and Shared Decision-Making among African-Americans with Diabetes," *Health Communication* 28, no. 6 (2013). ACE screening and trauma-informed care also highlight the centrality of deep listening, e.g. Miriam Brooks et al., "Trauma-Informed Care in General Practice: 'Findings from a Women's Health Centre Evaluation,'" *Australian Journal of General Practice* 47, no. 6 (June 2018).

than his OB/GYN counterparts: twenty minutes as compared to between five and ten minutes. Twenty minutes is much shorter than the often hour-long home visits Claire and Katy conducted. It is apparent that the fee-for-service reimbursement schematics underlying the office visit time crunch do not help build trust between clinicians and patients. However more time to listen, while important, is not the only factor in improving the basis upon which trust is built.

The goal of listening is to come to an informed understanding of the patient's health care values and how they are shaped by the factors in her life. This kind of understanding instills the trust necessary to engage in shared decision-making about big health care decisions that can shape trajectory of a woman's life story. Clinicians also need to be able to show that they care about each individual patient to gain their trust, and to do that, they must come to know and understand each patient's unique experiences that affect their outlook on health and well-being.

While the commitment of individual health care professionals to active listening and understanding their patients is vital, systemic changes to health care systems also need to occur to support and sustain this culture shift. Katy pointed out how practicing trauma-informed care and utilizing the ACES (Adverse Childhood Event Screening) tool is one way to help clinicians foster this kind of understanding about their patient's lives that includes a holistic re-tailoring of the entire health care experience. Trauma-informed care represents an approach to providing health care that is cognizant of how traumatic events in a person's history have significant impacts on their physical and mental health, and that when ill-prepared, health care institutions can contribute to re-traumatization instead of being a step toward healing. Trauma-informed care and the ACES tool help clinicians link together how events in one's childhood—from the availability of clean clothes to wear to school and whether their parents took them to doctor's

appointments to whether they were exposed to drug use or experienced abuse—correlate to higher rates of, for example, obesity and heart disease.<sup>29</sup> In layperson's terms, trauma-informed care flips the office visit narrative from "What's wrong with you?" to "What happened to you?" This reframing acknowledges the considerable role social determinants play in constraining the moral choices available for securing good health. Essential to trauma-informed care is training the entire staff of a health care delivery site—including practitioners but also front desk attendants, scheduling personnel, medical assistants, and environmental services providers—on what it means to be part of patient's health care experience, especially given the vulnerable place patients are often, possible experiences in their pasts, and the possibility of the sensitive and deeply personal nature of health care to either reopen a wound or be an opportunity for healing.

How do we as White people—as parents, health care professionals, church-goers, community members—recognize that our privilege comes at the disadvantage of others, renounce our complicity in racism, and move forward with compassion toward real solidarity? White Catholic feminist ethicist Mary Hobgood explains the engagement needed from White people interested in building solidarity, especially those in positions of relative social power:

The challenge for Whites is to see if we are capable of giving up the easy routes to assuaging our increasing vulnerability today. One route that leads to false self-comfort is supporting the intensified imperialism of late capitalism. Increased vulnerability in the population leads many to uncritical over-identification with a powerful nation. The other route of course is scapegoating, blaming White problems on diverse communities of color. Both flagwaving and scapegoating excuse Whites from the intellectual work of discerning the real source of our problems. White vulnerability I will argue is so ubiquitous that ultimately only solidarity, the necessary foundations for genuine

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<sup>29</sup>Vincent J. Felitti et al., "Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults: The Adverse Childhood Experiences (ACE) Study," *American Journal of Preventive Medicine* 14, no. 4 (May 1998): 245-258.

reparations, will save us from our worship of empire, our racism, and our own increasing insecurity.<sup>30</sup>

Hobgood points out how global forces of capitalism and imperialism are working to the disadvantage of the entire human community, including White people. Without dismissing how White people are vulnerable to these structures, she challenges us to recognize that others are suffering as well, and to greater degrees. Therefore we cannot be satisfied by failsafe practices that keep ourselves and our individual families afloat amidst the unjust structures of globalism. Hobgood cautions against “flagwaving,” or blindly buying into false nationalistic narratives that tie our dignity to consumerism and ultimately our own commodification. Again, she warns us of “scapegoating,” or blaming the suffering of White families on people of color, who are vulnerable to the same forces of globalism and often more acutely due to social location. To avoid these practices that lead to the worship of false gods, Hobgood sees that the only plausible answer to our shared human problem is solidarity. In her framing, solidarity is the foundation that can lead us toward genuine reparations.

### ***Metanoia: Conversion toward Compassion-in-Action***

Commitment to a foundational principle of respect for Black women’s dignity and agency is important for those with race, class, and/or gender privilege who want to work toward solidarity. A critical first step is honest interrogation of the blinders put up by one’s own privilege that distort our ability to respect Black women as well as perpetuate practices that disrespect them. For White people, this means owning the fact that our skin color affects our social mobility at the expense of others, and that implicit bias clouds our ability to connect with

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<sup>30</sup>Mary E. Hobgood, “Flag-waving Scapegoating, or Solidarity: The Challenge to Whites of the African-American Reparations Movement,” *Union Seminary Quarterly Review* 56, no. 1/2 (2002): 123.

those who are different than us. Considering, too, how intersecting social identities as a White woman or White man, a White person who works in health care or a White person who influences health policy or health care decisions, is an important part of this self-assessment particular to this contextualized solidarity. These experiences are part of *metanoia*, or a change of heart, that is necessary to engage in relationships of true compassion-in-action and become supporting players in partnership with Black women for social justice.<sup>31</sup> This section builds on the introduction of *metanoia* and compassion in Chapter Two, where I traced the Christian foundations of these terms and introduced them as practices fitting to the work of White anti-racism.

White Protestant feminist ethicist Jennifer Harvey's three moments of a reparations paradigm—remember, repent, and repair—provide helpful direction for White people engaging in *metanoia*. To remember means to cultivate historical consciousness that can reframe present-day disparities and help answer the question “How did we get here?” White people with social power have a lot of work to do to understand how the situation of Black women and families is affected by the historical legacy of racism in the US. We also have to ask ourselves how this history has shaped *us* as White persons. How does the legacy of treating human beings as property shows up in our social interactions with our families, neighbors, and co-workers? How does it affect the lens of policymakers and health care leaders whose decisions have vast impacts of the lives of people of color? Learning about the historical atrocities that social institutions,

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<sup>31</sup>*Metanoia* is an essential component of white Christian anti-racism that describes a conversion or change of heart that carries the sense of not only an intellectual commitment to thinking differently but an embodied transformation of how one sees oneself and the world. See a full discussion of *metanoia* in Chapter Two, pages 71-79.

including medicine, have perpetuated against Black women, and considering how our current reality is shaped by this past, is part of what it means to remember.

Repentance is decidedly more religious in tone, and draws from a longstanding Christian tradition of confessing transgressions and taking responsibility for one's actions. Harvey presents a decidedly White anti-racist understanding of repentance when she states that "[i]n a reparations paradigm, repentance replaces cultivation of multicultural sensitivity," pointing out that it is indeed White people who have particular work to do instead of a universalism about respecting everyone.<sup>32</sup> Harvey shows how both individual and communal acts of repentance are important parts of *metanoia*, and includes the drafting and ratification of commitments to anti-racism as part of the work of repentance. Imagining what a day of repentance for structural racism on the part of a health care system, social service agency, or government body could be a fruitful way to think about making amends for the historical abuses perpetuated by medicine, the government, and society at large against Black families.

Harvey contends that if *metanoia* is truly taking root, concrete acts of repair will follow closely after remembrance and repentance. For her, conversion of heart is necessary for repair. Within the reparations paradigm, repair means more than tolerance or inclusion. Repair is active and begins with the recognition that there is a void, a disparity, and an injustice that needs to be corrected. There are undoubtedly economic injustices that affect Black families at a disproportionate rate that can be addressed through reparations aimed at redistributing resources to make the health care system, as well as other social goods, equitable for all. There are also broken relationships with medical professionals, social service agencies, government bodies,

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<sup>32</sup>Harvey, *Dear White Christians*, 129.



churches, and other social institutions that need repair through changing the way people are treated on individual and social levels.

Harvey further names two important dimensions of the reparations paradigm: constructionism and particularity. She states,

It is for each community, in its own discrete locale, to take up this work, look around for how others are already approaching it, and generating creative, disruptive visions of what a reparations paradigm might mean for the racial relationships in which the community already dwells and seeks to live as part of a collective.<sup>33</sup>

What it means to remember, repent, and repair in the context of infant mortality in Milwaukee will need to be particular to our history, our current state, and our hope for what the future can look like given the needs of Black families and the changes in health care that will be needed in order to meet these needs. Here I am not only talking about physical needs, but also needs to be recognized and affirmed as respected members of the community whose lives matter deeply to the rest of the community.

Reparations can be uncomfortable for White people to talk about. This discomfort may come from the fear of having to give up benefits derived from the *status quo*, since reparations in popular use often refers to a redistribution of wealth to the descendants of enslaved African Americans. Harvey argues that reparations constitutes more than an economic component, and must include remembering racially-motivated sins of the past, repentance for transgressions, and repair not only of economic imbalances but social relationships across racial lines. Catholic woman religious Mary Elsbernd notes that “reparation has shifted in meaning from an individual

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<sup>33</sup>Ibid., 190.

effort to undo harm to structural and social change such that harm cannot occur again.”<sup>34</sup> This broadened conception of reparations likely adds to the discomfort White people might feel when asked to not only account for personal transgressions against people of color, but also our complicity in perpetuating social structures that disadvantage others based on race. However, this discomfort is a necessary step of practicing *metanoia* and working toward real solidarity.

Emilie Townes offers the following insights about what it means to have an honest dialogue about reparations today:

reparations talk, to my mind, is not ultimately about Black people...  
 in this country, when it comes to Black people  
 I believe reparations are about the ability or inability of Whites and their kin  
 to recognize they have attained their power and privilege on the backs of  
 the poor  
 the darker skinned  
 the feminine  
 and it just might be the time to have an honest conversation about this  
 deal with the denial and guilt it is sure to spark  
 and then talk about just what reparations might mean in empire<sup>35</sup>

Townes is calling for White people to engage in real conversation of what reparations means given our position within the globalized context Hobgood depicts. Once it is widely recognized that the power and privilege of many White people was built “on the backs of the poor/ the darker skinned/ the feminine,” what is a just and necessary repair to this brokenness? These are just the conversations that need to be had by those who have the power to affect the social structures contributing to Milwaukee’s infant mortality disparity.

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<sup>34</sup>Mary Elsbernd, “Social Ethics,” *Theological Studies* (February 2005): 151.

<sup>35</sup>Townes, “Empire and Forgottenness,” 113-114.

In the context of a White anti-racist response to the infant mortality crisis in Milwaukee, *metanoia* can be described as a conversion from apathy to solidarity. As shown by the disproportionate focus on parental behaviors and the prevailing message that Black parents are largely to blame for infant deaths, the combination of ignorance and disinterest regarding the plight of Black women in Milwaukee has led to a deep-seeded apathy in our society. A changing of our ways would constitute identification with Black moms instead of demonizing them. Recall Massingale's description of *metanoia* as a conversion or "fundamental shift in one's paradigm of understanding, interpreting, and acting upon reality."<sup>36</sup> Conversion would mean supporting Black families instead of refusing to dismantle structures that put them at disadvantage.

While some may have their heart strings pulled by hearing stories of Black families who have lost a child, it is not enough to feel bad for another, or even to identify with the pain that has been caused. As feminist philosopher Lisa Tessman astutely observes, empathy is important but not sufficient.<sup>37</sup> Recall Massingale's description of compassion as beyond sympathy and empathy, constituting "not only sorrow for and identification with, but *action* to meet the other's need. Compassion acts to alleviate the suffering of another."<sup>38</sup> Even if someone has the desire to move beyond empathy toward compassion, Massingale notes that there are significant barriers to compassion, including individualism, consumerism, and racism. Determining how to act compassionately given the toxic racism interwoven into unbalanced social structures that underlies infant mortality in Milwaukee is a difficult but important undertaking.

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<sup>36</sup>Massingale, *Racial Justice and the Catholic Church*, 121.

<sup>37</sup>Lisa Tessman, *Burdened Virtues: Virtue Ethics for Liberatory Struggles* (Oxford: Oxford University Press, 2005).

<sup>38</sup>Massingale, *Racial Justice and the Catholic Church*, 121.

The embeddedness of racism in health policy, health care, and social services warrants particular alarm, especially for those interested in a Christian bioethical response to infant mortality. Indeed, Massingale and Copeland name racism as more sinister than a social structure of sin; they denounce racism as idolatry.<sup>39</sup> Idolatry means the worshipping of false gods, or put another way, prioritizing and serving relationships that are contrary to God's intentions for human community. This religious language helps Christians understand racism for what it truly is: a turning away from God and community and toward the self. Racism can then be characterized by those with racial privilege turning away from relationships that affirm the dignity of all people, to instead participate in and benefit from the systemized disregard of the dignity of a group of people based on skin color.

A concrete example of this kind of conversion to compassion-in-action and making reparations is working to improve health insurance coverage and along with it access to good quality health care for people of color. Advocating for basic health care as a human right is an area noted by collaborators to this project as a place of budding solidarity. Recall that Physician Greg Johnson shared his view that just as everyone in our society has access to a basic education, they should have access to basic housing, food, and health care. Greg understands that having health insurance is a key component of access to health care, and he bemoaned employment structures that do not offer affordable health insurance. Additionally, Greg decried the possibility of placing constraints on eligibility for Medicaid based on compliance with drug policies, cognizant of the fact that those with substance abuse issues are often most in need of health care.

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<sup>39</sup>Bryan N. Massingale, "Has the Silence Been Broken? Catholic Theological Ethics and Racial Justice," *Theological Studies* 75, no. 1 (2014): 133-155; Bryan N. Massingale, "Response: The Challenge of Idolatry and Ecclesial Identity" in *Ecclesiology and Exclusion: Boundaries of Being and Belonging in Postmodern Times*, ed. Dennis M. Doyle et al. (Maryknoll: Orbis, 2012), 130-35; Copeland, *Enfleshing Freedom*, 109-110.

Recall that Luke Williams, also a physician, discussed the complicated ins and outs of health insurance eligibility, showing how the bureaucracy involved in navigating health insurance, even for those who are insured or who are eligible, can be a barrier to accessing care.<sup>40</sup> The disunity between recognizing that each individual person is worthy of receiving health care and the realities of US health insurance that result in barriers to care represents another instance of failed solidarity. Indeed, a commitment to reparations for the well-being of Black families must include removing bureaucratic barriers to insurance eligibility and health care access, and an overall commitment to basic education, housing, food, and health care for all.<sup>41</sup>

### **Mutuality and Accompaniment: “How Do We Walk Side by Side?”<sup>42</sup>**

Many of the collaborators to this project expressed frustration with failures to meet the practical needs of women and families. Remember Milwaukee mother Victoria’s experience of being homeless and single with six children, and then given a list of phone numbers for all of the housing services in Wisconsin. Victoria did not find this list helpful, and moreover, she was unconvinced that anyone on the other end of the phone line on that list would not be able to

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<sup>40</sup>See pages 164-165.

<sup>41</sup>Increasing Medicaid coverage itself is not the answer, given the lower reimbursement rates and therefore the different way care is provided. Some studies show that patients with low socioeconomic status perceive that their social status negatively affects the treatment they are provided, their access to care, and their interactions with their providers. See Nicholas C. Arpey et al, “How Socioeconomic Status Affects Patient Perceptions of Health Care: A Qualitative Study,” *Journal of Primary Care and Community Health* 8, no. 3 (2017): 169-175. Given that 13% of the United States population identifies as Black and 21% of Medicaid enrollees identify as Black, we know that Black people receive health insurance through Medicaid proportionally more than their White counterparts: Kaiser Family Foundation, “Medicaid Enrollment by Race/Ethnicity,” <https://www.kff.org/medicaid/state-indicator/medicaid-enrollment-by-raceethnicity/?currentTimeframe=0&selectedRows=%7B%22wrapups%22:%7B%22united-states%22:%7B%7D%7D%7D&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> (accessed December 4, 2018).

<sup>42</sup>Jo, focus group interview by author, Milwaukee, WI, July 29, 2017.

understand her situation as she told it to them.<sup>43</sup> In Chapter Three I pointed out how this kind of assistance by referral to a list of phone numbers actually disempowers the same women that these agencies are supposed to be supporting. Gaia's practical example of sitting down with someone, finding out if her phone has internet access, and making calls together presents a different way of interacting that is attentive to a woman's lived experience.<sup>44</sup> Jo asked an important question: "How do we walk side by side with each other, and other women, to help them and to follow up?"<sup>45</sup> Entering into another's life, even if only peripherally and for a moment, provides that needed connection between a social resource and how it can in reality meet a practical need. This kind of support represents mutuality and accompaniment, practices that are troublingly absent from some of the ways social and medical services are provided.

Mutuality and accompaniment are essential for practicing contextualized solidarity. Mutuality can be thought of as the recognition of oneself and others who occupy different social locations as interdependent partners in the quest for justice. White Christian social ethicist Rebecca Todd Peters considers mutuality as the starting point for relationships based in solidarity.<sup>46</sup> She states,

Developing relationships of solidarity across lines of difference is difficult and likely to be fraught with discomfort, misunderstanding, skepticism, and perhaps even hostility. In seeking to build these new relationships, the value of mutuality must be ever at the forefront of one's mind and heart. These relationships cannot be forced onto others but must arise out of contexts of trust and mutual vulnerability."<sup>47</sup>

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<sup>43</sup>See page 116.

<sup>44</sup>See pages 115-116.

<sup>45</sup>See page 115.

<sup>46</sup>Rebecca Todd Peters, *Solidarity Ethics: Transformation in a Globalized World* (Augsburg: Fortress Press, 2014), 115.

<sup>47</sup>*Ibid.*, 118.

Cognizant of the difficulties of building trusting relationships given historical patterns of disrespect, Peters shows how, for those in places of privilege, mutuality is tied to recognizing shared vulnerability and seeking a change of heart. She holds:

Cultivating a moral agency of mutuality encourages people to recognize the core humanity of each person while also challenging them to examine the structures of society that impoverish others (for example, lack of access to education, insufficient compensation, lack of jobs, poor nutrition, and healthcare).<sup>48</sup>

Mutuality, then, is both a way of engaging in relationship across lines of difference and also a self-reflexive approach to considering how individual social benefits are tied to another's social needs remaining unmet. As Peters concludes,

Once we are able to move to a position of mutuality as the starting point for our moral reflection, we are able to exercise our moral agency in ways that reflect an understanding of the deep interdependence of our lives with the lives of all peoples and creatures on the earth.<sup>49</sup>

In the context of infant mortality in Milwaukee, mutuality would ideally come to describe the relationship between Black women and those governmental, social, and health care supports that are charged with respecting their dignity and agency, as outlined earlier in this chapter.

Real mutuality is a lofty goal given unequal social power dynamics, and there is admittedly plenty of room for well-intentioned persons with privilege to get it wrong. However, working in tandem with commitments to respect for Black women's dignity and agency and to White anti-racist *metanoia* as described above, mutuality is a helpful framework for recognizing that the thoughts and actions of those who benefit from the *status quo* have real consequences for those disadvantaged by the same systems. It is not enough to mean well. We must be held

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<sup>48</sup>Ibid., 45.

<sup>49</sup>Ibid., 94.

responsible for the outcomes of our choices, especially those unduly influenced by racial bias or that lack from the outset critical self-reflection. In the medical context, mutuality presents a strong argument against paternalism because it holds that patient and clinician are interconnected and their particular bodies of knowledge are both necessary for coming to a decision that carries out the patient's values and is medically sound. In its best sense, mutuality holds those in places of privilege accountable for their actions that have unfavorable outcomes for Black women and families.

When it comes to respecting a Black women's dignity and agency in individual patient-clinician, patient-client, or support group relationships, mutuality can be lived out through accompanying her on her journey. Accompaniment is a practice rooted in Christian tradition. While spiritual accompaniment can refer to individual or group pastoral counseling, accompaniment is often used to describe the model of relationship between church members engaged in global missions for solidarity and the communities they partner with in other parts of the world. While there is a growing body of work in Christian ethics about global solidarity, Peters rightly points out that relationships of solidarity across lines of difference may just as likely be across town.<sup>50</sup> Accompaniment is also used to describe the relationship between seriously ill and dying patients and their caregivers—often those family caregivers, home-visiting nurses and therapists, and community health workers who develop long-term caring relationships outside the walls of the clinic and in the home or community.<sup>51</sup> One way of

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<sup>50</sup>Ibid., 105.

<sup>51</sup>M. Therese Lysaught, "Geographies and Accompaniment: Toward an Ecclesial Re-ordering of the Art of Dying," *Studies in Christian Ethics* 29, no. 3 (2016): 286-293; John Sherrington, "The Journey of Accompaniment," *Studies in Christian Ethics* 29, no. 3 (August 2016): 294-300.



defining accompaniment that can encompass each of these relationships is “walking together in a solidarity that practices interdependence and mutuality.”<sup>52</sup> Walking together is perhaps the most important part of accompaniment, accentuating that being with others on their journey—and ensuring you are not the pilot, but instead are present to support a person as she directs her life—is at the heart of what it means to accompany.

There are a few key reasons why mutuality and accompaniment are especially fitting for building contextualized solidarity in Milwaukee around women’s and infant health. They are guiding concepts for forging relationship grounded in listening to women about their social and health needs and validating both women’s agency and the role of those in places of social power to work to advance the conditions necessary for good health. Mutuality and accompaniment involve establishing relationships over time, something my collaborators see as necessary for building trust. They also prioritize a narrative of partners on a journey, where women are the authors of their own life stories and clinicians, support group leaders, and policymakers and other decision makers support them by removing those stumbling blocks identified by women that are within their realms of control.

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<sup>52</sup>Consider this description of the Evangelical Lutheran Church in America (ELCA) world mission: Walking and working together, we seek to *accompany* our companions. Accompaniment is defined as *walking together in a solidarity that practices interdependence and mutuality*. The ELCA lives out accompaniment in relationships with global companions, striving to share God’s love and participate in God’s mission together:

- Mutually: All of us have gifts to support God’s mission. There is no mission *to*, only mission *with* and *among*.
- Inclusively: We seek to build relationships across boundaries that exclude and divide.
- Vulnerably: Just as Jesus became vulnerable to us, we open ourselves to others.
- Empowering: We seek to identify and correct imbalances of power, which may mean recognizing and letting go of our own.
- Sustainably: To ensure local ministries last for a long time, we seek to embed mission in ongoing relationships and communities, <https://www.elca.org/Our-Work/Global-Church/Global-Mission>.

Accompaniment also represents a way of becoming part of a woman's support system. Becoming part of a woman's support system is a promising way to move toward solidarity. Remember Victoria and Monet, Milwaukee mothers and support group members, who both lifted up their relationships with mental health professionals and their Strong Baby Sanctuary support group as integral parts of their support systems. Victoria said that of the little support she does have, her therapist is "a big help," and is someone she trusts and can talk with openly. Monet likewise shared that the main person she can talk to is her therapist. Both Victoria and Monet affirmed that the Strong Baby Sanctuary support group is an important part of their social support system, and that meeting together in the church can help other women too.<sup>53</sup> It appears that key components of becoming part of a woman's social support system include offering a protected place and time for a woman to openly share intimate life stories with others who are trusted. Building this kind of trust takes concerted effort, and leads into some of the insights from my collaborators who are health care professionals.

Mutuality and accompaniment can be considered the actions that stem from the key components of solidarity identified earlier in this chapter. What does it mean to respect women's dignity and agency in a responsible and historically conscious way? How do I practice compassion in conversation? How can I recognize experiences that call for me to change my ways? Reflecting on whether and how mutuality and accompaniment are present (or not) in relationships—either with individual women, groups, or in decisions that shape health practices and policy—can be a good measure of whether one is engaging in solidarity. While it is

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<sup>53</sup>Victoria Jefferson and Monet Washington, focus group interview by author, Milwaukee, WI, July 29, 2017.

important to grasp the fullness and nuance of the key components of contextualized solidarity, it is also helpful to have some ready concepts as a check for one's mindset and actions. Mutuality and accompaniment are accessible, and can be presented as teachable concepts of attitudes and approaches that are rooted in respect for Black women's dignity and agency, *metanoia*, and compassion.

### **Living Into Contextualized Solidarity: Recommendations for Responding to Milwaukee's Infant Mortality Crisis**

Clinicians, health care leaders, churches, public health workers, elected officials, policymakers, community organizers, and bioethicists—to name a few—all have a role to play in addressing Milwaukee's racial disparity in infant mortality. Each of these groups will be called to engage in different kinds of actions depending on their proximity to women and infant health care and the reach of their influence. Certainly, social location matters. While the spheres of influence for each of these groups are distinct, they do overlap. Some of these recommendations are geared more toward one or two of these particular stakeholders that would generally be responsible for implementation, yet each of these partners can contribute to the advancement of all of these practices. Here are some examples of the kinds of concrete efforts that can be undertaken by partners committed to reducing racial disparities in infant mortality and overall infant deaths. Each recommendation is both an important factor in itself and is integrally related to the other recommendations so that the success of each is necessary for the success of a holistic reimagining of how we should respond to the crisis in infant mortality.

### **Recommendation #1: Practice Centering Pregnancy**

There are a growing number of emerging, promising, and best practices for delivering prenatal and primary care to women and infants that use an accompaniment model. Centering Pregnancy is one well-known model. In contrast to the traditional model of one-on-one prenatal care, Centering Pregnancy groups women who have similar due dates so they may receive prenatal care together. A midwife or nurse practitioner facilitates a group of 8-12 women and their support persons through ten 90-minute sessions that incorporates prenatal assessments, education, and support. Developed by a midwife, Centering Pregnancy is “an interdisciplinary model of empowerment” that encourages parental agency, leading to “a shift in the client-provider power base.”<sup>54</sup> Benefits for women who are part of this program have been shown to include increased social support, improvement in mental health and greater satisfaction with care.<sup>55</sup> There is some evidence that group prenatal care results in decreased risk of preterm birth (especially for African American women), small for gestational age, low birthweight and reduction in Caesarean sections. However, not all studies replicate these findings.<sup>56</sup>

For all of its merits, there are indeed barriers to the success of a Centering Pregnancy model of care. One study found varied and limited understanding about their Centering Pregnancy program among clinic staff, which affected referrals to the program as well as

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<sup>54</sup>Sharon Schindler Rising, “Centering Pregnancy: An Interdisciplinary Model of Empowerment,” *Journal of Nurse-Midwifery* 43, no. 1(1998): 46.

<sup>55</sup>S.D. Cunningham et al., “Prenatal Care Attendance: Determinants and Relationship with Care Satisfaction,” *Journal of Maternal and Child Health* 21, no. (2017): 770-776.

<sup>56</sup>A.H. Picklesimer et al., “The Effect of Centering Pregnancy Group Prenatal Care on Preterm Birth in a Low-Income Population,” *American Journal of Obstetrics and Gynecology* 206, no. 5 (May 2012): 415.e1-7.

referrals for women in the program to other services the clinic provided.<sup>57</sup> Additionally, when clinics attempt to implement a Centering Pregnancy program without a dedicated coordinator, there are issues with clear communication and knowledge sharing about the model, gaining referrals, coordinating group schedules, and securing financial resources that may be in use by other programs. This last point is tied to cost as a barrier: some Centering Pregnancy initiatives have been successful because they have received grant funding for a program coordinator and other resources. Consider the findings of a study that looked at the implementation of Centering Pregnancy in six urban clinics:

All sites had barriers to meeting the model's demands, but how sites responded to these barriers affected whether implementation thrived or struggled. Thriving sites had organizational cultures that supported innovation, champions who advocated for CP+, and staff who viewed logistical demands as manageable hurdles. Struggling sites had bureaucratic organizational structures and lacked buy-in and financial resources, and staff were overwhelmed by the model's challenges.<sup>58</sup>

It is helpful to think how mutuality and accompaniment can make a difference in the successful implementation of these kinds of programs.

The JJ Way is a unique derivation of the Centering Pregnancy model that is attentive to the specific needs of under-resourced women of color.<sup>59</sup> The JJ Way is informed by the fact that race and class do make a difference in birth outcomes, and therefore that particular attention needs to be paid to the needs of each woman who faces these realities. While the needs of a

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<sup>57</sup>Kania-Richmond, Ania et al., "The Impact of Introducing Centering Pregnancy in a Community Health Setting: A Qualitative Study of Experiences and Perspectives of Health Center Clinical and Support Staff," *Journal of Maternal and Child Health* 21 (2017):1332.

<sup>58</sup>Novick et al., "Perceptions of Barriers and Facilitators during Implementation of a Complex Model of Group Prenatal Care in Six Urban Sites," *Research Nursing Health* 38, no. 6 (2015): 462-474.

<sup>59</sup>The JJ Way Model of Maternity Care, Association of Maternal and Child Health Programs Innovation Station, 2009, <http://www.common sensechildbirth.org/wp-content/uploads/2011/05/JJ-way-AMCHP-Best-Practice.pdf> (accessed November 2, 2018)

pregnant woman are individual, many individual needs can be met in a group setting, and women can benefit from sharing their experiences and entering into the experiences of others who may face similar challenges. At the same time, having those who are different from you hear your story and learning from the experiences of someone different from you has the benefit of building support across the boundaries of class and race that, in our daily lives, we may not have the opportunity or courage to cross.

### **Recommendation #2: Grow the Doula Movement**

Another prime example of accompaniment is the doula movement that provides one-on-one support for women through the birthing process. A doula is “a trained professional who provides continuous physical, emotional and informational support to a mother before, during and shortly after childbirth to help her achieve the healthiest, most satisfying experience possible.”<sup>60</sup> Certified doulas abide by standards of practice and a code of ethics, which not only includes important principles for the doula-client relationship, but also ethical responsibilities to society and community service. This includes promoting maternal and child welfare, and the specific vision of “a doula for every person who wants one,” including a provision to provide doula services at a reduced cost, if possible, or making appropriate referrals, as available.<sup>61</sup> Some doulas advocate for the benefits of peer-to-peer support that can be offered by African American doulas to Black women from someone who knows what it’s like to “live in their skin”—meaning someone who shares the experience of dealing with the pressures of being a woman of color in

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<sup>60</sup>DONA International, “What is a Doula?,” <https://www.dona.org/what-is-a-doula/> (accessed August 28, 2018).

<sup>61</sup>DONA International, “Code of Ethics: Birth Doula,” <https://www.dona.org/wp-content/uploads/2017/08/COESOP-2017-FINAL-Birth.pdf> (accessed August 28, 2018).

contemporary US society. The doula model gives another example of how mutuality and accompaniment can be lived out in a patient-clinician relationship.

### **Recommendation #3: Further Develop Reproductive Health Care Core Competencies**

How can clinicians improve pre-conception, prenatal, and postpartum visits? Given what was learned from collaborators in this project, we need to improve clinician competencies in screening for violence and connecting patients to mental health care, engaging in reproductive counseling in a way that supports women's agency, and overall fostering relationships of trust that embed clinicians in their patients' support systems. Recall Luke William's struggle to balance what he knows from the literature about the rates of unplanned pregnancies among his patient population and the importance of listening to each woman's particular life story and supporting her control over her body. A change in focus from the goal of choosing a long-acting contraceptive to a goal of supporting a woman as she directs her own family plan is warranted. This would not mean that family planning is not an important part of patient-clinician visits, but it would change the framework of that conversation from one that is focused on discussing the options and making a choice to one that affirms a woman's role as choice agent in her reproductive future and the clinician as a supportive character in that woman's narrative.

### **Recommendation #4: Change Health Care Business Models**

Significant change has to occur within not only health care providers, but their leaders as well, for these values to be put into practice. Consider my experience talking to a nurse manager about the ultimate goal of having less babies born premature meaning we would have less babies stay in the NICU. She had just finished a rigorous proposal process to add three more NICU beds, and is tasked with keeping them full. Mentally she

knows that less babies born premature is a good thing, however she finds it ironic that she is also conditioned to see an empty NICU as bad for business. There is significant room here for health care leaders to challenge reimbursement models to incentivize care that is just.

### **Recommendation #5: Improve Health Insurance and Reimbursement**

Health care leaders, elected officials, and policymakers can attend to disparities perpetuated by our current health insurance system. For example, consider how being insured by Medicaid affects care. While the parameters around qualification for coverage and reimbursement rates are within the scope of government policymakers, hospital system budgets and parameters (or lack thereof) for clinicians to accept patients with Medicaid are within the scope of health care leaders. For enhancements to be made in the kinds of programs or services covered by Medicaid, the two need to work together to ensure that Medicaid patients will have access to these services and that it is fiscally sustainable. In all, to confront Milwaukee's infant mortality problem we need a principle that is cognizant of the history of racism in our city; that takes ownership for the complicity of medical, governmental, and church institutions in advancing health disparities; and that is serious about restoring relationships currently plagued by mistrust and unbalanced power.

### **Recommendation #6: Combat Violence and Mass Incarceration**

Government officials and health care leaders need to make a concerted effort to play their part in reducing the violence in women's and men's everyday lives. Recognizing that people of color are more likely to experience violence can help build understanding that any response to



violence needs to be informed by the power dynamics of race in society. Elected officials and health system leaders can support initiatives like the Milwaukee Blueprint for Peace.

Building on the evidence of the prevalence of violence in Milwaukee begun in Chapter Three, many types of violent activities are prevalent in our city. Gun violence, sexual violence and human trafficking, child maltreatment and exploitation, car-jacking, domestic and intimate partner violence, structural violence, drug-related violence, and self-directed violence/suicide/self-harm are all named in the Blueprint for Peace as areas of concern. Guided by the principles of community, equity, individual and community resilience, and action, the Milwaukee Blueprint for Peace “establishes clear direction and a call to action for a public health approach to violence prevention that engages community residents and multiple sectors.”<sup>62</sup> It is described as “a living document to guide action,” and encourages individuals and organizations to “review and utilize the Blueprint to inform coordinated actions for violence prevention.” The blueprint for peace acknowledges that in Milwaukee in 2016 there were 139 lives lost due to homicide. It also notes from 2010 to 2016 a 76% increase in firearm-related homicide victims, and a 38% increase in nonfatal shooting victims. It links these deaths to health care costs, noting that “the average inpatient discharge costs for firearm-related injury for Milwaukee county residents with firearm-related injuries (135 cases total) were \$68,678.”

### **Recommendation #7: Ensure Fair Pay and Working Conditions**

Midwives, medical assistants, community health workers, doulas, and faith community nurses, who evidence shows help achieve good birth outcomes, need to be compensated fairly for

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<sup>62</sup>414 Life: Milwaukee Blueprint for Peace, <https://city.milwaukee.gov/414Life/Blueprint#rates> (accessed August 28, 2018).

the important work they do.<sup>63</sup> For example, given that Centering Pregnancy is an evidence-based practice that is shown to have outcomes at least as successful as traditional patient-clinician one-on-one visits, it could be argued that these programs ought to be reimbursed at a comparable rate. Given that a midwife, not a physician, facilitates this group, and that 8-12 patients can be seen at once, it is likely that it is reimbursed at a much lower level, that without grant funding, may not be self-sustaining even though it costs less than the traditional model overall. Health care systems, social service agencies, and government bodies paying the salaries need to respect community health workers and advocate for reimbursement for their services that is on par with the hard work they do and the contributions they make to healthier communities. If we want people to do these jobs well, we need to support their ability to earn a living wage and support their own families. With a lack of respect and lack of financial resources, we will not be able to find highly qualified people to fill these positions.

Caring for women in resource-stressed contexts warrants not only just compensation, but institutional support including security and work-life balance. Gaia acknowledges the tension that exists between the work that she loves to do and the fact that in order to do it, she is sometimes in situations that makes her family worry. She relates, “My children and my family worry about me. It's like, ‘Girl, when you gonna get another job? When you gonna do something different?’ It's like, ‘This is where I – this is what I love. This is what I do.’” To alleviate some of the stress related to the geography in which she works, Gaia stays away from social media: “I'm not on Facebook. I don't do Twitter or anything like that because that's one way to help keep

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<sup>63</sup>Abigail Rian Evans, *Is God Still at the Bedside? The Medical, Ethical and Pastoral Issues of Death and Dying* (Grand Rapids: Eerdmans Publishing Company, 2011). 363-364.

down my anxiety of working in this city.”<sup>64</sup> I take this to mean that it is easier to get through the day without constantly being notified of the violence happening all around you. Gaia’s sense of commitment to the people of her neighborhood acts as a source of strength and resilience for her, encouraging her to stay while it may be tempting to find a job that makes her feel safer, pays better, and has her family less concerned for her well-being. We need to support people who are willing to do community health work: it needs to pay well, have benefits, include continuing education, be connected to advancement and leadership opportunities, and ultimately be recognized for the important role it plays in the lives and health of women and families.

### **Recommendation #8: Revamp Cultural Competency through Medical Education**

Sixteen years ago, in 2002, the Institute of Medicine (IOM) Report recommended cultural competency training as one way to help counteract racial health disparities.<sup>65</sup> In her 2006 ethnographic work on health disparities faced by Black and Latina women with breast cancer, White Christian social and medical ethicist Aana Marie Vigen recommended, among other practices, increasing cultural competency among health care professionals. She wrote,

By cultural competence training, I mean integrated attention to racial-ethnic, socioeconomic, linguistic, cultural, and religious particularities that shape patient needs, perceptions, experiences of health and illness, needs, and fears with which they contend. Such education must teach *both* appreciation of the complexity of others’ lives as well as critical self-reflection.<sup>66</sup>

Indeed, cultural competency training that can meet the goal of increasing knowledge and understanding among health care providers about social determinants of health and how implicit

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<sup>64</sup>Gaia Earth, focus group interview by author, Milwaukee, WI, July 29, 2017.

<sup>65</sup>Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, The National Academies of Sciences, Engineering, Medicine, 2002.

<sup>66</sup>Vigen, *Women, Ethics, and Inequality*, 188.

bias contributes to these would be welcome. We could then look forward to an outcome of more clinicians who pause to check their biases, really listen to the patient in front of them for her/his unique story, and in turn make the patient feel the respect s/he deserves. However as Vigen notes, without incorporating social analysis and rigorous self-critique, “brief diversity trainings held for current healthcare professionals can fall short of what is needed.”<sup>67</sup>

How are we doing twelve years after Vigen’s recommendations, and sixteen years after the IOM Report? While cultural competency training is now common in educational offerings for health care professionals, there is concern that it is not as well developed as it could be. Critics note that some cultural competency trainings come off as canned lip service to diversity and inclusion without those critical elements of social analysis and self-critique Vigen describes as essential. The discomfort of addressing privilege due to social location, which could be especially helpful for those of us whose White fragility is a stumbling block, is often left out when the focus is placed on learning more about diverse cultures than contemplating the social power dynamics that disadvantage some to the benefit of others. Instead of spreading the message that we all harbor implicit bias that has harmful effects, including disparities in health care between racial/ethnic groups, it may be that health care professionals walk away from these trainings with a superficial notion that we are all unique and different and that should be celebrated.

Another potential downfall is that these trainings may be watered down to a means of avoiding civil rights complaints. Worst of all, poorly done cultural competency training has the potential to reinforce harmful stereotypes without spending time to unpack and dismiss them. As

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<sup>67</sup>Ibid., 189.

Vigen cautioned, “Culturally competent care involves more than learning about different foods, beliefs, and religious practices of patients. It must also rigorously and self critically analyze the socioeconomic and political forces that structure healthcare institutions and practices themselves.”<sup>68</sup> A starting point for improving the cultural competence of clinicians in Milwaukee would be education about the history of racial discrimination in Milwaukee, especially when it comes to Black families. Attention to historical medical practices that abused and disadvantaged people of color would be another important element to broaden the effectiveness of these trainings.

To this point, Gail and I discussed the weaknesses of cultural competence training. She shared these thoughts about what kind of education could help strengthen resident physicians’ understandings of their patients’ situations:

I do not know if the medical examiner would let them, but going into a death scene investigation. Going into a family’s home and sitting with them. And sitting where you don’t feel comfortable, and not saying anything. And just listening to another professional do all the talking and do all the work, that kind of thing. But I don’t know that you find a lot of... first year residents who are willing to do that... There’s people in urban medicine, that do an urban medicine rotation. It’s an elective, it’s like, a month. Big deal. Live it for a year and see what you can do. I don’t think a month is anything, or a couple weeks is anything. And a rotation or an elective is not a good idea... go sit there and learn it. I think ER and urban medicine should be mandated across the board.

Gail’s first recommendations about sitting in a patient’s home, listening, and learning from another professional, all echo accompaniment practices discussed above, which could indeed apply to a model for physician home visits. Gail’s further thoughts point out the limitations to elective or rotation-based exposure to what she refers to as “urban medicine.” There are also problems with that term—if “urban medicine” means practicing medicine in an

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<sup>68</sup>Ibid., 190.

urban area, then all of a resident's training in Milwaukee would be urban medicine, wouldn't it? If "urban" is stand-in for people of color, then why not call it a rotation focused on investigating social determinants of health, including questions like why Black people have overall poorer health than other racial/ethnic groups? The name isn't so much the issue, though, as the incredibly short time spent learning about the disadvantages Black families experience when it comes to their health.

Related more precisely to resident cultural competency regarding health disparities in infant mortality, Gail named a high-risk obstetric clinic and a midwifery clinic in the inner-city, with the exhortation to "go sit there." Her recommendation again recalls the accompaniment model, that by spending time and walking with a woman through her pregnancy and birth experience, important lessons can be learned about disparities in health care. I responded to Gail, reflecting on this proposal in light of her earlier comment on the length of rotations, and agreed that a month is not enough. Thinking about medical student rotations for obstetrics, I hypothesized a situation where a resident might say, "I went to Milwaukee, and I delivered all these Black babies for a month. You should have seen the types of single moms I spoke with. And now I'm back in Madison, whoop-de-doo." (Upon reflection, my statement here is rather cynical, but nonetheless grounded in some of the experiences medical students have shared with me.) I shared my thoughts that a month is almost just enough to scandalize the experience of caring for pregnant Black women and delivering their babies—especially poor, single Black women in an urban city like Milwaukee. The word I was searching for was "salacious"—which now I think I meant scandalize—but honestly salacious is true too. Because underlying the thoughts about the morality of getting pregnant while single—the scandal—are also false and

harmful salacious stereotypes about the promiscuity and sexual irresponsibility of Black women. If the entirety of a medical student's experience delivering babies is going to be with Black women in Milwaukee, there is significant work to be done before, during, and after this experience on the part of the students and their faculty members to ensure that Black women are respected and that they and their children—and literally, their bodies—are not used as means to ends.

Gail followed up by naming another problem: that medical students and residents are unlikely to practice where they train. She points to the fact that the bulk of health care professionals who serve Black women and families in Milwaukee are either not embedded enough or around long enough to build relationships of understanding and trust. Examples include working in the inner-city but living in the suburbs, or doing residency training in Milwaukee but ultimately taking a job in another area. She pointed to how these situations create discontinuity in patient care, and also a lack of understanding of the racialized social fabric of Milwaukee.

### **Recommendation #9: More People of Color in Health Professions and Positions of Leadership**

Another necessary part of being culturally competent is recruiting and retaining people of color in the health professions, and offering mentoring and advancement opportunities into leadership positions. Vigen astutely observes that “[m]ore leadership of darker skinned people within healthcare will transform cultures of institutions in ways that a number of diversity training can.”<sup>69</sup> She describes research that point out how the fields within the health professions

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<sup>69</sup>Ibid., 191.

do not adequately represent people of color, especially in leadership positions.<sup>70</sup> Comparing her assessment to more recent data, it is clear that there is still more work to do. Statistics from 2011-2015 show that out of 30 health occupations, 23 are overrepresented by White people when compared to their makeup within the overall US population.<sup>71</sup> Those occupation groups within the health professions where minority groups are well-represented are more likely to belong to the category “Healthcare Support and Personal Care and Services Occupations.” For example, Black people have the highest representation within the profession of “Nursing, Psychiatric and Home Health Aids”: 32.0% compared to their racial/ethnic group making up 11.6% of the US population.<sup>72</sup> The awareness of these differences helps to contextualize the issue of increasing diversity in the health professions. What kinds of interracial experiences are patients having when they are more likely to encounter a Black person than a White person as a home health aide, but reversely more likely to have a White person than a Black person as their doctor? Vigen makes a strong case for increasing people of color not just in the health professions overall but particularly in provider and leadership roles.<sup>73</sup>

### **Recommendation #10: Take Time to Listen**

Those working in health care are ever cognizant of time, or the lack thereof. But how much time does it really take to listen to patients? What would happen if health care

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<sup>70</sup>Ibid., 192.

<sup>71</sup>US Department of Health and Human Services, Health Resources and Services Administration, Bureau of Health Workforce, National Center for Health Workforce Analysis, “Sex, Race, and Ethnic Diversity of US Health Occupations (2011-2015),” August 2017, <https://bhw.hrsa.gov/sites/default/files/bhw/nchwa/diversityushealthoccupations.pdf> (accessed December 1, 2018).

<sup>72</sup>Ibid., 5-7.

<sup>73</sup>Vigen, *Women, Ethics, and Inequality*, 192.



professionals not only allowed, but encouraged, patients to express their thoughts and concerns uninterrupted? Recall Claire Smith's advice to clinicians about listening to their patients:

I think for providers, taking your time, really listening to your clients, being respectful of them and their wishes and their wants... Sitting down, talking to their clients, and teaching them... And talking about options. And explain yourself. Don't just tell them, 'This is how it's going to be.' Really explain yourself. Really listen to the client.<sup>74</sup>

Despite many clinicians' fears of a patient talking for an extended period of time, and threatening to put their entire schedule that day even more behind than normal, this concern is likely unfounded. In fact, one study on the subject found that the average patient will speak for 92 seconds if uninterrupted when responding to the initial question "What can I help you with today?"<sup>75</sup> A minute-and-a-half is all the time it takes (more or less) for a patient to voice her chief concerns. For pregnant patients who are in the middle of an established pattern of routine visits, it could conceivably take even less time to catch the clinician up on what has changed since their last visit. It is necessary to reframe excellent communication skills—including active listening, motivational interviewing, clarifying questions, teach-backs, and other evidence-based practices—as not one important tool but rather the essential vehicle for delivering quality patient care.

Those of us in places of relative social power need not only to support listening to patients—we need to listen to community residents and partners too in order to get a full picture of the needs of our families. Ethnographic work like that included in this project, including focus groups, qualitative interviews, participatory action research, and other community-based

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<sup>74</sup>See pages 166-167.

<sup>75</sup>W. Langewitz et al., "Spontaneous Talking Time at Start of Consultation in Outpatient Clinic: Cohort Study," *British Medical Journal* 325 (2002): 682-683.

listening is essential to coming to realistic understandings of the interrelatedness of health and social problems. In preparation for the defense of my dissertation, I presented some of this work to the Strong Baby Sanctuary Advisory Council to get their feedback. The responses of the council members affirmed that much of what I presented reflected their own experiences working with women, infants, and health professionals in Milwaukee. Our discussion then turned to naming important areas for further follow up and more research, some of which are highlighted prominently in this dissertation, some that are mentioned tangentially, and some that are less present and deserve further work. These topics include recruiting, retaining, and mentoring more people of color into health care leadership; how limited access to services for housing, homelessness, maternal mental health, and maternal learning disabilities constrains agency; increasing access to role models for young Black women; a focus on the increasing racial segregation and economic inequality; and the need for better and more transparent discussions of family planning and birth control options not just between patients and their providers but health care leaders, churches, and public health personnel as well.

### **Recommendation #11: Gather More Data**

My research brought to light some areas where it would be helpful to have more data. For example, infant race is categorized according to the mother's race. This recordkeeping practice does not account for biracial children. It would be helpful to know about differences in infant mortality causes and risk factors based on both biological parents', mom's and dad's, racial and ethnic heritage. Additionally, while the health department reports the percentage of infant deaths due to prematurity that had certain risk factors, it does not report how race is related to risk factors for prematurity. For example, while it is reported that 51.5% of infant deaths had

maternal infection (STD or UTI) during pregnancy as a risk factor, and 43.6% had the risk factor of maternal exposure to secondhand smoke during pregnancy, it is not reported whether there are racial disparities in infant deaths related to maternal infection or smoking. Transparent reporting of these statistics could help recognize the complexity of the social location of Black women, and help counter the false narratives that blame Black parents. It would also be helpful to gather more narrative information from Black women in Milwaukee who experience infant death, which undoubtedly would call for more funded positions to expand the follow-up already provided.

### **Recommendation #12: Support Churches**

Katy acknowledged the important role that churches have in supporting people in times of need. She knows that many of her clients rely on their faith communities for support, and envisions a church that is connected to social resources, prays with those in need, and ultimately fosters a sense of community. She shared, “My experience working with families is that the church is where they go when they’ve exhausted all their other resources. Being prepared to help connect them with someone or someplace in the community that can help meet their immediate need.” I responded that in addition to being connected, it is equally important for churches to understand that when people come to the church in need, they have often times exhausted all of their options, and therefore they need to extend some trust to that effect. Katy agreed, saying, “In my experience, they’ve already asked every family member and every friend and they’ve gone to the food pantry already. People are really resourceful and really resilient in getting their needs met, in my experience.”

### **Recommendation #13: Reimagine Roles and Principles for Bioethics**

In particular, bioethicists who work for health systems have a role to play when it comes to reframing responses to infant mortality. Too often the purview of a health care ethicist is narrowly scoped to focus on ethical issues directly related to patient care and the relationships between individual patients and care teams. While clinical ethics consultation is an important part of the ethicist's job, it certainly not the only or arguably the main role. Advising health care leaders about important issues and guiding them through decision-making processes is a key role of the ethicist. While the issues raised to the level of leader input should be informed by the kinds of ethical issues faced in patient encounters, it also needs to be informed by health-related trends in the greater community. Ethicists have a duty to pay attention to trends in public health and social determinants, and connect with clinical leaders to provide support and resources for considering what kinds of training for health care professionals and programming for patients can have a positive impact in Black women's lives, and the lives of their families and children. Examples could include conducting an in-service with leaders in obstetrics to lay out the case for why increasing physician training in trauma-informed care and ACES utilization is a responsible way to allocate time for physician education. Another example could be meeting with clinic leaders who are considering starting a Centering Pregnancy program or who want help making the case that another social worker to work with pregnant women at their clinic is a good investment for maternal and child health.

Indeed, to address the problem of infant mortality and the contributing racial disparities, we need a bioethics that is attentive to sociological analysis of power dynamics at the intersection of race, class, and gender and informed by the voices and experiences of those

closest to the problem. How do those of us who consider ourselves bioethicists allow the voices of the marginalized challenge how we prioritize our work? Do we take the time to connect more traditional ethics consultations in the NICU about withholding/withdrawing life-sustaining interventions to the underlying unjust racial and social conditions? Just as we see advance care planning as an upstream and proactive ethical response to end of life ethical dilemmas in the adult ICU, attention to racial disparities and social determinants in women's and infant health care must become a proactive ethical imperative. It is not only on policymakers, community leaders, and clinicians to change their ways. As bioethicists, we must as well. Taking seriously the principles I recommend of respect for Black women's dignity and agency (as a critique of respect for autonomy), *metanoia* as a White anti-racist practice of conversion to active compassion (as a critique of paternalistic beneficence), and mutuality and accompaniment (as acts of solidarity that leads to justice) can engender a bioethical framework that can adequately consider and analyze socially and racially complex issues like infant mortality and encourage concrete resolutions that are contextualized to the needs of Black women.

### **Conclusion**

This project has provided a vantage point informed by perspectives of those closest to the issue in order to reframe discussions of what ought to be done to address disparities in infant mortality and move toward solidarity with Black women, infants, and families. In revealing through statistical data analysis and review of the medical literature that the majority of infant deaths in Milwaukee are due to prematurity, of which there are multiple and systemic risk factors outside of parental control, Chapter One unveiled the inaccuracy and irresponsibility of portraying the root cause as "parents behaving badly." Chapter Two appealed to Christian

bioethics to take seriously the impact of race/class/gender analysis, discussed key sources and norms that are important with respect to infant mortality, and presented ethnography as one method attentive to social power dynamics that that is helpful for this kind of investigation. In Chapter Three, we heard from Milwaukee mothers and support group leaders about how violence and stress, as well as social hierarchy and “feeling less than,” both present barriers to health for women and infants, and also how they push against these barriers through faith and resiliency. Chapter Four listened to those working daily to address disparities in infant mortality, and revealed some promising insights for policy and practice change, while at the same time some disconnects in understanding how race/class/gender complicate women and infant’s health. In light of what has been learned in the preceding chapters, this chapter took up the question of what solidarity should look like by providing examples of failed solidarity, spelling out key components of a contextualized solidarity specific to infant mortality in Milwaukee, and giving some recommendations for taking steps on the path toward solidarity.

It is abysmally clear that the false narrative that Black parents are to blame for the disproportionate infant mortality rate of Black infants is a prime example of failed solidarity. The fact is that the majority of Black infants die due to causes related to prematurity. Prematurity is not solely or even mostly within a pregnant woman’s control, and there is a racial disparity between Black infants and those of other races who die due to prematurity. Therefore since it is not unsafe sleep but prematurity that is causing racial disparities and the vast number of Black infant deaths, and since we know that the reasons underlying prematurity are affected by socioeconomic and racial structures of disadvantage, it is not only inaccurate to say that Black parents are to blame, but it is a failure to stand with Black parents and demand better for their

children. Narratives that locate Milwaukee's infant mortality crisis within "the Black community," or focus disproportionately on safe sleep or maternal health without addressing social and racial determinants to a proportionately higher degree, are glaring signals of failed solidarity.

In the Strong Baby Sanctuary Program, parish nurse Mary Evans has developed support groups that present one image of solidarity with Black women in Milwaukee. This solidarity has been replicated on a small scale by others like Missy and Sister Faye who have started their own Strong Baby Sanctuary support groups. Based on her fourteen years of experience leading the group at her church, here is one way Mary describes the group's purpose:

Our basic thing was to try to decrease the stress during the pregnancy and that first year. Stay connected to them. We would meet, they would come, they would tell us what was going on with them. Sometimes even your problems don't seem so bad when you expose the light to it. And we would help them. The girls got close together, supported each other... they're going through many of the same things. We're just teaching them normalcy... and that social support.<sup>76</sup>

Mary highlights that this approach is unique because of the faith-based discussions around family values, seeking generational wisdom, and what it means to be a mother. While these discussions are paired with education about topics in prenatal and infant health, it is clear how motifs of accompaniment, mutuality, and ultimately respect are what make the Strong Baby Sanctuary approach meaningful to Milwaukee women.

Support groups like those led by parish nurses and church volunteers through the Strong Baby Sanctuary Program play important roles in women's support systems. For women like

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<sup>76</sup>At this point in our discussion Mary was talking about when she first started and most of the participants were teenagers, hence her use of the term "girls" instead of "young women" which she used more often in our conversation.

Monet and Victoria who experience racism, classism, gender oppression, the kind of emotional and spiritual support provided by Strong Baby Sanctuary groups is a safe-haven and refuge from the violence and disrespect they experience daily. While these kinds of support groups are immensely important to many women's support systems and therefore necessary to continue, they are on their own wholly insufficient for correcting the underlying social ills that allow the infant mortality crisis to persist. While groups like these should be funded more so than they are so that they can continue to reach more women, simultaneous work from many other sectors is required on personal and especially systemic levels to create real and lasting solidarity with Black women, infants, and families.

On a larger level, we need to change social policy so that women's, men's, and children's needs for safety, housing, jobs that earn a living wage, and equitable health insurance and health care are prioritized over the financial interests of businesses and individuals. We also need to prioritize these complex large-scale strategies especially when it is easier to put our focus elsewhere. We can come to reimagine solidarity as a principle that is historically-minded, conscious of race/class/gender disparities, and that begins with the recognition of concrete injustices in our midst. In this light, then, a contextualized solidarity attentive to the struggles of Black women in Milwaukee must rest upon a principle of respect for persons that affirms the dignity of all by prioritizing those who have been put last. Solidarity is formed by the recognition that those of us in places of power need to account for our own failures and the failures of the institutions we represent to respect and care for Black women and families.



APPENDIX A  
RECRUITMENT LETTER

Dear Potential Collaborator:

I am a doctoral candidate at Loyola University Chicago. My dissertation is titled “Retrieving and Reimagining Sanctuary and Solidarity: Racial Disparities in Infant Mortality.” Its goal is to identify and develop practices rooted in social justice and interracial solidarity that can help health care providers and community health workers address socioeconomic and racial disparities that manifest in the lives of African American women, infants, and their families.

I seek to conduct one-hour interviews with physicians and community health workers who serve African American women, infants, and their families within Milwaukee. Specifically, I aim to interview 3-6 physicians and 3-6 community health workers. I want to speak with physicians who provide prenatal, obstetric, and infant care to this population; and I want to speak with community health workers who primarily work with this population. My goal in interviewing these groups is to gain insight into how barriers to healthy births and infant health are linked to socioeconomic factors and institutional racism. I want to learn which practices are successful in mitigating the effects of socioeconomic and racial health disparities, and where opportunities for intervention exist. As individuals committed to infant health who work directly with pregnant women, infants, and their families, you are uniquely positioned to reflect on rich experience and offer concrete narrative that can have an impact on improving our community’s response to racial disparities in infant mortality.

I am currently looking to interview physicians and community health workers with experience serving pregnant African American women, infants, and their families who are interested in discussing how socioeconomic factors and racism create barriers to healthy births and healthy infants. If you are interested in participating in this research project, please send me an email at [acapp@luc.edu](mailto:acapp@luc.edu) or call me at -----.

Thank you,

Alyson Capp

Faculty Sponsor: Aana Marie Vigen, PhD

APPENDIX B

INTERVIEW QUESTIONS

1. How long have you been involved in community health efforts in Milwaukee?  
Specifically infant mortality and racial health disparity issues?
2. Tell me about the population you serve: what is their demographic makeup in terms of socioeconomic class, education, race/ethnicity, gender, insurance status, and religious affiliation?
3. What do you most love about working with pregnant women, infants, and their families?  
What do you find to be most challenging?
4. What practices have you seen to be successful in improving prenatal and infant health?  
What is necessary for these practices to work?
5. What barriers do you see to prenatal and infant health in our community? What do you think are some of the root causes?
6. While navigating the prenatal and infant health care terrain, do you or those you serve experience the effects of individual or institutionalized racism? What do these experiences look and feel like?
7. What role do you think you and others like you play in building cross-racial solidarity?
8. If you could address a room of doctors who care for pregnant women and infants, what would you want them to know about health disparities, prenatal care, and infant health?
9. If you could address a room of faith leaders in Milwaukee, what would you want them to know about health disparities, prenatal care, and infant health?
10. Do you see any policy changes that could be addressed at the grass roots or governmental levels by community organizations or faith communities that could have a direct impact on reducing health disparities in infant mortality?
11. What role, if any, does the context of working or partnering with a faith-based institution play in your work? Does faith or religion play a role in how you interact with pregnant women, infants, and their families?
12. How do you describe your social location, related to race/ethnicity, socioeconomic class, education, gender, and religious affiliation, if any?

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## VITA

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